

**Camouflaging in Autism: An Individualistic Strategy in Response to a
Stigmatised Social Identity?**

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Chapter I:

Executive Summary

The current project investigates factors relating to wellbeing in those with stigmatised social identities, specifically disabled and autistic¹ people.

Chapter two is a systematic review of the quantitative literature investigating the relationship between disability identity and psychological wellbeing.

Chapter three is an empirical study examining the theory that camouflaging represents an individualistic strategy in response to the stigmatised social status of autism. Chapter four integrates findings from chapters two and three and discusses their impact and dissemination.

Systematic Review: What is the relationship between disability identity and psychological wellbeing?

Disabled people are found to report lower psychological wellbeing than non-disabled people and wellbeing tends to reduce following disability onset.

Understanding the factors that relate to disabled people's wellbeing is key to the development of effective services for disabled people. The present study systematically reviewed quantitative research investigating the relationship between disability identity and wellbeing.

¹ Identity first language (e.g. autistic person) as opposed to person first language (e.g. person with autism) is used throughout, following the finding that identity-first language was preferred by the majority of autistic people (Kenny, Hattersley, Molins, Buckley, Povey, & Pellicano, 2016).

Disability identity is defined as the extent to which one claims disability status as part of one's identity and feels connected to other disabled people. It is often used interchangeably with 'disability acceptance', which refers to accepting one's self as disabled and viewing disability as non-devaluing. Recent research has found that greater disability identity predicted psychological wellbeing above and beyond functional impairment and symptom severity. The findings indicate that disability identity could constitute a key factor in disabled people's wellbeing, as this systematic review investigated.

Social Identity Theory (SIT) proposes that members of stigmatised groups, such as disabled people, adopt strategies to manage the effects of stigmatisation involving rejecting or embracing their stigmatised identities. SIT predicts that both rejecting and embracing disabled identity could protect wellbeing by either reducing direct discrimination or promoting within-group self-esteem.

In line with SIT predictions, the qualitative and quantitative research appeared to demonstrate both positive and negative relationships between disability identity and wellbeing. However, many of these studies explored behaviours consistent with embracing or rejecting a disability identity (e.g. disability concealment or disclosure) and did not measure participants' disability identity. There was also a significant variation in the populations sampled amongst these studies, for example, specific disabled populations versus a

range of disabilities and adult versus child populations. These factors, alongside SIT processes may account for the apparent variability in the literature. This study aimed to examine these factors in a systematic review of the quantitative research exploring the relationship between disability identity and wellbeing.

Two reviewers conducted systematic literature searches using PsychInfo and Web of Science, followed by manual searches of the included articles. The search algorithm included variants of identity, disability and psychological wellbeing. Studies with child populations and qualitative methods were excluded. Forty-six articles were identified by the initial search and 17 studies were included in total. Initial interrater reliability was moderate.

The included studies exhibited considerable variability in their designs, populations sampled and operational definitions of disability identity and psychological wellbeing. A quality assessment tool was developed which assessed the appropriateness of the included studies' samples, handling of confounding factors, measures and statistical analyses. The overall quality of studies was relatively good.

A narrative synthesis of the results was performed. The combined results indicated that generally measures of disability identity positively correlated with measures that indicated higher psychological wellbeing (e.g. self-esteem, quality of life and satisfaction with life) and negatively correlated with measures that indicated poorer psychological wellbeing (e.g. depression and

anxiety). Similarly, participants categorised as having higher disability identity scores demonstrated higher wellbeing scores (quality of life) and participants with lower wellbeing (higher depression scores) demonstrated lower disability identity scores.

The results suggest that greater identification with being a disabled person is associated with greater psychological wellbeing. Given that the majority of the designs included were cross-sectional, correlational and/or differential, neither causation nor the direction of the relationship between disability identity and psychological wellbeing can be inferred.

Compared to the qualitative and quantitative findings outlined previously, the reviewed studies present more consistent findings. The possible reasons for this are explored, including the review methodology (e.g. the exclusion of child populations, and qualitative designs) and features of the included papers (e.g. the disabled populations sampled, and measures of disability identity and wellbeing utilised).

Two notable exceptions to the overall trend in the results (where disabled identifying participants demonstrated equal self-esteem or greater mental health problems compared to non-disabled identifying participants) are considered in relation to their large, general population samples and single-item measures of disability identity. The possible confounding role of social support when recruiting via disability organisations in the majority of the other studies is also considered. It is concluded that whilst there are pros and cons

to using both methodologies, the general population samples and single-item measures are deemed most likely to limit the generalisability and validity of the results.

The strengths and limitations of the data are discussed leading to a number of implications for future research. Greater longitudinal research is required to explore the relationship between disability identity and wellbeing over time as well as the potential underlying mechanisms. Further, the use of standardised measures of disability identity are recommended. The review process is also critiqued (e.g. the search strategy, interrater reliability and use of a 'bespoke' quality assessment tool) leading to recommendations for future replications.

Finally, the clinical implications of the results are considered. It is argued that the reviewed evidence indicates that encouraging the development of a disability identity, that includes developing connections with disabled people and adopting non-devaluing values (as opposed to simply categorising oneself as disabled) has the potential to be beneficial for wellbeing.

Finally, it is concluded that the results find greater identification with being a disabled person is associated with greater psychological wellbeing across a range of adult disabled populations.

Empirical Study: Camouflaging in Autism: An Individualistic Strategy in Response to a Stigmatised Social Identity?

Autistic people typically show differences in their social communication, sensitivity to sensory stimulation and focused nature of their interests.

Camouflaging refers to strategies autistic people may adopt to mask or minimise features of autism in order to “pass” as non-autistic.

The International Classification of Diseases (ICD) called for clinicians to be aware of camouflaging behaviours when assessing autism, as camouflaging is hypothesised to relate to the late and misdiagnoses of autism, particularly in women. Camouflaging is also important for understanding the clinical needs of autistic people. Qualitative research has repeatedly shown autistic people relate camouflaging to experiencing poorer psychological wellbeing. Further, a small number of quantitative studies have demonstrated that self-reported camouflaging is linked to lower psychological wellbeing. Identifying why autistic people camouflage and how camouflaging relates to wellbeing may enable better support for autistic people, by reducing the reasons people camouflage or identifying ways of camouflaging that do not relate negatively to wellbeing.

One theory that may explain the relationship between camouflaging and wellbeing is that camouflaging represents a response to the stigmatisation of autism. There is much evidence to suggest that autism is stigmatised, indicating the utility of understanding autistic experiences through the impact

of stigma. As outlined, SIT proposes that when social identity is stigmatised, people use strategies that aim to protect their sense of wellbeing.

Camouflaging may be likened to SIT's individualistic strategies that involve dissociating from one's stigmatised group (e.g. autistic people) and attempting to join or "pass" into a higher status group (e.g. non-autistic people). Whilst individualistic strategies are thought to reduce discrimination (protecting wellbeing) they are also theorised to reinforce the group's devalued status, potentially increasing internalised stigma (reducing wellbeing) and reducing in-group connections (also reducing wellbeing).

Whilst the qualitative findings provides some support for these theories, in order to assess whether camouflaging may be understood as an individualistic strategy in response to a stigma, the current study examined the hypotheses that measures of camouflaging: 1) positively relate to experiences of autism-related stigma, 2) positively relate to individualistic strategies and negatively or shows no relationship to collective strategies², 3) negatively relates to wellbeing and 4) mediate the relationship between stigma and wellbeing.

Three-hundred and two participants (184 female, 61 male and 56 non-binary identifying) autistic adults were recruited via online and offline communities.

Participants were mostly white and university educated. An official autism

² Collective strategies are theorised (by SIT) to contrast with individualistic strategies. They include embracing the group identity and aims to re-define its de-valued status through collective action.

diagnosis was not required to participate. Presence of autism was confirmed using a diagnostic screening tool.

Participants completed measures of individualistic and collective strategy use, camouflaging, autism-related stigma, wellbeing, autistic traits and a series of demographic questions via an online questionnaire. A cross-sectional, single group, correlational design was used.

A multiple regression found that stigma (alongside younger age, older age at diagnosis and female gender) positively related to camouflaging, supporting hypothesis one. A hierarchical regression found individualistic and collective strategy use predicted greater camouflaging, partially supporting hypothesis two. Another hierarchical regression found greater camouflaging predicted decreases in wellbeing, supporting hypothesis three. Finally, a mediation analysis found stigma had a negative effect on wellbeing, which was mediated by camouflaging, supporting hypothesis four.

The findings suggest camouflaging could be motivated by a desire to avoid experiences of stigma and discrimination, which fits with qualitative accounts of camouflaging and research into concealing autistic traits. Although related to individualistic strategy use, camouflaging is found to differ in its positive relation to collective strategy use suggesting it may co-occur with embracing autistic identification and the autistic community. It may be argued that camouflaging, like individualistic strategies, negatively impacts on wellbeing by reinforcing or failing to challenge the stigmatised status of the group.

Lastly, the findings could provide support for the theory that camouflaging accounts for later diagnoses, particularly in women.

Limitations of the research methodology are discussed, including the generalisability of the sample, recruitment method, and cross-sectional design. Implications for clinical practice are discussed, including the need for anti-stigma interventions for the general population, the potentially stigmatising role of clinical interventions and the need for clinicians to be aware of camouflaging alongside other barriers to diagnosis.

It is concluded that camouflaging relates to experiences of stigmatisation and lower wellbeing, and whilst it bears similarities to an individualistic strategy, it differs in its positive relation to collective strategy use.

Integration, Impact and Dissemination

Integration

Both the empirical study and systematic review shared a theoretical grounding in SIT, enabling some integration of their findings. For example, the extent to which one identifies with one's social identity (such as being disabled or autistic) is theorised to relate to the use of individualistic and collective strategies. Previous research has found that greater disability identity related to greater collective strategy use. Accordingly, given the negative relationship between camouflaging and wellbeing found in the empirical study and positive

relation between disability identity and wellbeing observed in the systematic review, one may expect that camouflaging relates negatively to autistic identity. Similarly, the mechanism through which disability identity relates positively to wellbeing may be further understood by examining the role of collective strategy use that the empirical study found to relate positively to wellbeing.

Challenges of both chapters are explored, including the lack of adjustments to facilitate the participation of people with learning disabilities or impairments and a lack of expert by experience involvement in the systematic review. Implications for future research are discussed.

Impact

Systematic Review

The results of the systematic review have important implications for a variety of individuals involved in disabled people's lives, who play a role in shaping disability identity development and subsequently wellbeing. For example, rehabilitation professionals, educators, and caregivers, who are often non-disabled, have a key role in introducing disabled people to the disabled community to aid disability identity development. It is also argued that, practitioners should shift their understanding of their role from experts who "fix" disabilities to allies of the disabled community in order to place value in disability experience and aid positive identity development.

The results also indicate the importance of accessible spaces to develop and maintain disabled communities. This implication is of particular relevance to policy makers, local councils and charities who play a role in funding and ensuring accessibility of spaces. Similarly, the results may reinforce the importance of online disabled communities, which are found to challenge dominant disability narratives and support identity development.

Finally, the results may have implications for educational settings. Some research suggests that disability specific teaching (e.g. hard of hearing classes) within mainstream settings enables connection between disabled peers and disability identity development.

Empirical study

The results of the empirical study also have important implications for a variety of individuals. By demonstrating the relationship between stigma, camouflaging and wellbeing, the results may help to re-frame camouflaging from an 'individual problem' to a 'societal problem'. This conceptualisation places responsibility on society, and in particular policy makers, educators and researchers to reduce autism-related stigma to increase the wellbeing of autistic people.

To reduce stigmatisation, autistic self-advocates recommend that organisations move from advocating for a cure for autism to campaigning for increased acceptance, accommodations, and support. Individual members of

society may reduce their own stigmatising attitudes by seeking greater knowledge of autism and connection with autistic people.

The findings also emphasise the need for clinicians to be aware of camouflaging during assessment for autism and during therapy.

Consequently, the findings indicate the need for information on camouflaging during clinical training on autism.

Dissemination

Academic

Both the systematic review and empirical study will be submitted for publication in academic journals. For the systematic review, *Disability and Rehabilitation* and *Clinical Rehabilitation* and for the empirical study, the *Journal of Autism and Developmental Disorders* has been selected to target initially. Each journal selected have impact factors between 1.77 and 3.47, indicating relatively wide readerships.

Applications will also be submitted for poster presentations at academic conferences to increase the size and diversity of the academic readership. The *World Disability & Rehabilitation Conference* has been identified for the systematic review and *The International Conference on Stigma* for the empirical study.

Community

Short summaries of the projects, written in plain English with visual aids will be distributed amongst relevant communities (e.g. disabled or autistic people, charities, support groups and community organisations) via email and social media.

Clinical

Short presentations, summarising the empirical study and systematic review will be developed to present to clinical psychologists and allied professionals working in relevant local services (e.g. autism diagnostic services, psychological therapies and rehabilitation).

Chapter II: Systematic Review:

What is the relationship between Disability Identity and Psychological Wellbeing?

Abstract

Disabled people are found to report lower psychological wellbeing than non-disabled people and wellbeing is found to reduce following disability onset. Understanding the factors that relate to disabled people's wellbeing is key to the development of effective services for disabled people. The present study systematically reviewed the empirical evidence investigating the relationship between disability identity and wellbeing. Two reviewers conducted literature searches using PsychInfo and Web of Science, followed by manual searches of the included articles. The search algorithm included variants of identity, disability and psychological wellbeing. Child populations and qualitative methods were excluded. Forty-six articles were identified by the initial search and 17 studies were included in total. The included studies sampled a range of disabled populations including adults with brain injury, multiple sclerosis, acquired and congenital mobility difficulties, learning disabilities and post-colostomy surgery. A "bespoke" quality assessment tool found the overall quality of studies to be relatively good. A narrative synthesis of the results was performed. The combined results indicated that measures of disability identity positively correlated with measures that indicated higher psychological wellbeing (e.g. self-esteem) and negatively correlated with measures that indicated poorer psychological wellbeing (e.g. depression). Similarly,

participants categorized as having higher disability identity demonstrated higher wellbeing and participants with lower wellbeing demonstrated lower disability identity. It was concluded that greater identification with being a disabled person is associated with greater psychological wellbeing across a range of disabled adult populations. The reviewed evidence would suggest that encouraging the development of a disability identity, that includes developing connections with disabled people and adopting non-devaluing values (as opposed to simply categorising oneself as disabled) could be beneficial to wellbeing.

Introduction

Psychological wellbeing is a broad concept which refers to positive interpersonal and intrapersonal functioning (Burns, 2016). It can include self-referent attitudes (e.g. self-esteem), environmental mastery (e.g. satisfaction with life) and mental health difficulties (Burns, 2016; Ryff, 1989). Disabled people are found to report lower psychological wellbeing than non-disabled people and wellbeing tends to reduce following the onset of disability (Dijkers, 1997; Lucas, 2007). However, little is known about the factors that impact on the wellbeing of disabled people (Smedema, Catalano, & Ebener, 2010). Understanding the factors that relate to disabled people's wellbeing is key to the development of effective services for disabled people, such as support, residential care and rehabilitation services (Smedema et al., 2010).

Disability identity is defined as the extent to which one claims disability status as part of one's identity and feels connected to other disabled people (Dunn, 2014; Shakespear, 1996). It is often used interchangeably with 'disability acceptance', which refers to the process of accepting one's self as a disabled person and adapting one's value system to view disability as non-devaluing (Wright, 1960; 1983). Recent research with adults with multiple sclerosis and brain injury found that greater disability identity predicted psychological wellbeing above and beyond functional impairment and symptom severity (Bogart, 2014; Ditchman, Sung, Easton, Johnson, & Batchos, 2017). These findings indicate that disability identity could constitute a key factor in disabled people's wellbeing. The present study aims to systematically review the

literature investigating the relationship between disability identity and wellbeing. This section will consider how disability identity is theorised to relate to wellbeing, outline the empirical evidence and how the present review will take account of, and investigate the apparent discrepancies in the literature.

The rehabilitation and counselling literature largely draw on Wright's (1960; 1983) disability acceptance theory to understand the potential relationship between disability identity and psychological wellbeing (Crewe, 1999; Livneh & Antonak, 2005). Wright (1960; 1983) outlines four value changes involved in the disability acceptance process; 1) enlarging the scope of values; 2) containing the impact of the impairment; 3) de-emphasizing the importance of physical appearance; 4) focusing on strengths rather than comparative abilities. Such changes are considered to enhance psychological wellbeing by prompting the development of coping strategies, a positive sense of identity and future goals (Deloach & Greer, 1981; Livneh, 2001; Livneh & Antonak, 2005).

However, Wright's (1960; 1983) theory is criticised for lacking applicability to a range of disabilities and conceptualisations of disability (Bogart, 2014). For example, Keany and Gluekauf (1993) highlight that the theory assumes disability involves a misfortune and/or functioning loss, which may be less applicable to people with congenital disabilities. Further, disability scholars argue that the negative aspects of disability are largely socially constructed through social stigma and a lack of accommodations (Olkin, 1999). From this

perspective, the relationship between disability identity and psychological wellbeing may be better understood from a “minority model” perspective, that recognises the role discrimination, prejudice and disadvantage have in shaping disabled people’s identities and wellbeing (Olkin, 1999).

Social Identity Theory (SIT; Tajfel & Turner, 1979) emphasises the role of societal stigma in shaping identity and wellbeing (Bogart, 2014; 2015; Nario-Redmond, Noel, & Fern, 2013). It proposes that members of stigmatised groups, such as disabled people, risk poor psychological wellbeing due to the low esteem in which their group is held (Tajfel & Turner, 1979). It theorizes that individuals protect their wellbeing by adopting one of two strategies (Tajfel & Turner, 1979). Individualistic strategies involve distancing one’s self from the stigmatised group and attempting to “pass” as part of the higher status group (i.e. rejecting a disabled identity) potentially reducing one’s experience of direct discrimination and protecting wellbeing. Collective strategies involve affirming one’s stigmatised identity, seeking group contact and advocating for the group’s value (i.e. embracing a disabled identity) (Nario-Redmond et al., 2013). Collective strategies are theorized to protect wellbeing through promoting favourable within-group comparisons, attributing discrimination to out-group prejudice, emphasising group strengths and devaluing group “weaknesses” (Crocker & Major, 1989; Tajfel & Turner, 1979). Accordingly, SIT (Tajfel & Turner, 1979) suggests both embracing and rejecting a disability identity could relate positively to wellbeing via either individualistic or collectivistic strategies.

The qualitative and quantitative research demonstrate both positive and negative relationships between disability identity and wellbeing. In qualitative research, people with learning disabilities, visual impairments or autism have linked concealing their disabled status with high levels of stress, anxiety and guilt due to the effort and shame involved in “passing” as non-disabled (Barga, 1996; Hull et al., 2017; Spiegel, De Bel, & Steverink, 2015). This would indicate that hiding a disabled identity could negatively impact on wellbeing, suggesting claiming a disabled identity would be more beneficial to wellbeing. However, adolescents with physical disabilities have reported greater discrimination and isolation following disability disclosure (Lynch & Gussel, 1996) indicating that claiming disabled status could also negatively impact on wellbeing.

Quantitative research using proxy indicators of disability identity has also found both rejecting and embracing relate positively to wellbeing. Fernández, Branscombe, Gómez, and Morales (2012) found contact with disabled people (which is consistent with embracing disability identity) and obtaining procedures that minimise impairment (e.g. limb lengthening surgery, consistent with rejecting a disability identity) were both protective of psychological wellbeing for people with disproportionately small stature (dwarfism). Together with the qualitative research, the literature presents inconsistent findings indicating rejecting and embracing a disabled identity may relate both positively to wellbeing.

However, a difficulty with interpreting the qualitative findings and data using proxy measures is that they refer to actions consistent with embracing or rejecting a disability identity (e.g. concealment, disclosure, community contact or impairment minimising) but do not measure a person's sense of disability identity. Disability identity refers to claiming disability status, connection to other disabled people and holding non-devaluing beliefs about disability (Dunn, 2014; Wright, 1983). The actions captured in the above studies may only refer to aspects of disability identity (e.g. claiming status or connection to disabled people) rather than the full concept of disability identity. It could be that such different aspects of disability identity relate differently to wellbeing, accounting for variability in the findings. This systematic review intends to examine how quantitative measures of disability identity relate to wellbeing to better understand these discrepancies.

However, studies that measure disability identity or acceptance also present inconsistent findings. Research with some distinct disabled populations such as people with multiple sclerosis, brain injury and spinal cord injury have found positive correlations between positive disability identity, life satisfaction and self-esteem (Bogart, 2014; Ditchman et al., 2017; Smedema et al., 2010). Whereas studies sampling a range of disabilities have found that rejecting a disability identity is linked with lower rates of mental health problems (Olney, Kennedy, Brockleman, & Newsome, 2004).

These findings could indicate that the relationship between disability identity and wellbeing may vary by disability or disability specific factors (e.g. acquired

versus congenital, life limiting versus life threatening) (Bogart, 2015). As has been noted, aspects of disability acceptance (i.e. acceptance of loss and value change) may be less relevant to people with congenital disabilities (Keany & Gluekauf, 1993). Equally, strategies to reject a disability identity (e.g. “passing”) may be more or less available depending on one’s disability (e.g. visibility and nature of impairment; Joachim & Acorn, 2000). In order to consider whether the relationship between disability identity and wellbeing differs amongst specific disabilities or disability specific factors this review intends to examine a range of disabilities rather than one specific disabled population.

Olney et al. (2004) also highlights that definitions of psychological wellbeing vary considerably within the disability identity literature. For example, in the studies outlined thus far wellbeing has been defined by the presence or absence of anxiety, stress, self-esteem, satisfaction with life and mental health difficulties (Bogart, 2015; Spiegel et al., 2015; Olney et al., 2004). Whilst this may be indicative of the broad nature of wellbeing as a concept (Burns, 2016) it complicates interpretation of the findings since different relationships may exist between disability identity and different facets of wellbeing. Accordingly, to better understand the discrepancies in the results, this systematic review intends to examine how disability identity relates to different definitions and measures of wellbeing as well as the overall trend across measures of wellbeing.

Olney et al. (2004) also suggests research with children and adolescents may obscure understanding of disability identity and wellbeing. Childhood and adolescence are theorised to be periods of fluctuation and change in identity development (Erikson, 1968). As a result, the relationship between disability identity and wellbeing may vary throughout childhood and adolescence and differ to relationship found in adults. This suggests adult and child populations should be investigated separately. This systematic review intends to focus on the relation between disability identity and wellbeing in adults.

In sum, the considerable variability in the literature on disability identity and wellbeing may be accounted for in SIT processes, the diversity of measures utilised and participants sampled. Systematic investigation is required to examine the relationship between disability identity and wellbeing amongst different disabled populations and consider how measures of disability identity and wellbeing may impact on the relationship. Therefore, this systematic review aims to examine the relationship between disability identity and psychological wellbeing across a range of quantitative measures of disability identity and wellbeing in adult populations.

Methods

Protocol

The methods used in this review were informed by the Centre for Reviews and Dissemination (2008) guidance for undertaking systematic reviews and follows the Preferred Reporting Items of Systematic reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009) guidelines. A search was performed in January 2018 at the International Prospective Register for Systematic Reviews to ensure that a similar review had not been previously performed or registered.

Eligibility Criteria

Articles were eligible for inclusion if they: A) utilised quantitative or mixed methods (where the present review question is addressed using quantitative methods); B) utilised experimental, cross-sectional or longitudinal designs; C) were available in English; D) focused on adult participants (those 18 years or over) with a disability (physical or learning disability); E) utilised measures of disability identity (including disability acceptance or denial) and psychological wellbeing (including quality of life, satisfaction with life, self-esteem, anxiety, depression or mental health difficulties). Published and unpublished research were accepted, and no criteria was specified for the time period of publication or authorship. Studies with participants comprised exclusively of psychiatric patients were excluded.

Information Sources

Two reviewers (E.P. and a research assistant) conducted independent systematic two-step literature searches to identify relevant articles. First, PsychInfo and Web of Science were searched to find published and unpublished studies in August 2018 and November 2018. Second, manual searches of the reference lists and contents of the included articles were performed. Where a relevant full-text publication was not available, the main authors were contacted directly to request a manuscript.

Search Strategy

The search algorithm included the following terms and related variants; identity (self-categori*, acceptance, disclosure, hidden, concealed, “disability identity”, self-ident*), disability (disab*, impairment, handicap), psychological well-being (“life satisfaction”, “mental health”, “mental illness”, “mental disorder”, “psychological distress”, depression, anxiety, “self-esteem”, “self esteem”, happiness, QOL, “quality of life”, “well being”, “well-being”). The Boolean operator AND was used to combine the three search term categories (identity, disability and psychological wellbeing). Searches were limited to ‘within titles’ for these terms and variants. Boolean operator NOT was used for the search term categories children (youth*, “young people”, “young person”, child OR teenager*, adolesce*) and qualitative. These terms and variants were searched for ‘within full texts’ for PsychInfo and ‘within topic’ for Web of Science.

Study Selection

The two reviewers independently screened all titles and abstracts for inclusion. If the reviewer(s) considered that an article could match the inclusion criteria, the full paper was obtained and independently screened. Any disagreements about inclusion or exclusion of articles were resolved by discussion. Initial interrater reliability was moderate, Cohen's $k = 0.55$.

Quality Assessment

Given the limited availability of brief quality assessment tools that are suitable for multiple research designs (Boland, Cherry, & Dickson, 2014) a quality assessment tool was developed specifically for this review. Following Boland et al.'s (2014) guidance, a checklist system (as opposed to scoring system and total score) was developed to provide detail around the individual elements of study quality. The tool was adapted from the Critical Appraisal Skills Program (Singh, 2013), Mixed Methods Appraisal Tool (Hong et al., 2018) and the Quality Assessment Tool for Quantitative Studies (Thomas, 2003). It includes eight questions over four domains (sample, confounding factors, measurements and statistical analysis). Sample items include, "sample is adequately described", "standardised measures are used" and "statistical analysis is appropriate for study design". Items are checked as "yes" (adequately addressed), "no" (not adequately addressed) "partially" (partially addressed) or "unclear" (insufficient information is provided). Further details of the quality assessment tool are available in the appendices (appendix 1).

Synthesis of Results

As the designs and statistical procedures of the obtained studies varied considerably (e.g. cross-sectional, prospective, correlational and differential) a statistical synthesis of the results was not considered useful or feasible. Accordingly, a narrative synthesis (i.e. textual description of the results) (Boland et al., 2014) was considered most meaningful. Given the diversity in operational definitions of disability identity and psychological wellbeing, the results were organised by each concept (e.g. self-esteem) and measure (e.g. Rosenberg's (1979) Self-Esteem Scale) used to define each term.

Results

The PRISMA flowchart is shown in Figure 1. Eight out of the 46 articles identified by the initial search and nine out of the 37 articles cited within those studies were available and deemed eligible for inclusion. Seventeen studies were included in total, comprising 149,713 participants with a range of disabilities. All studies included adults over 18 years old except two (Bat-Chava, 1994; Chalk, 2016) which included a small proportion of younger participants. Bat-Chava (1994) included participants aged 16-87 (mean age 42.9) and Chalk (2016) did not report the age range of participants but noted 94% fell between 18-25 years.

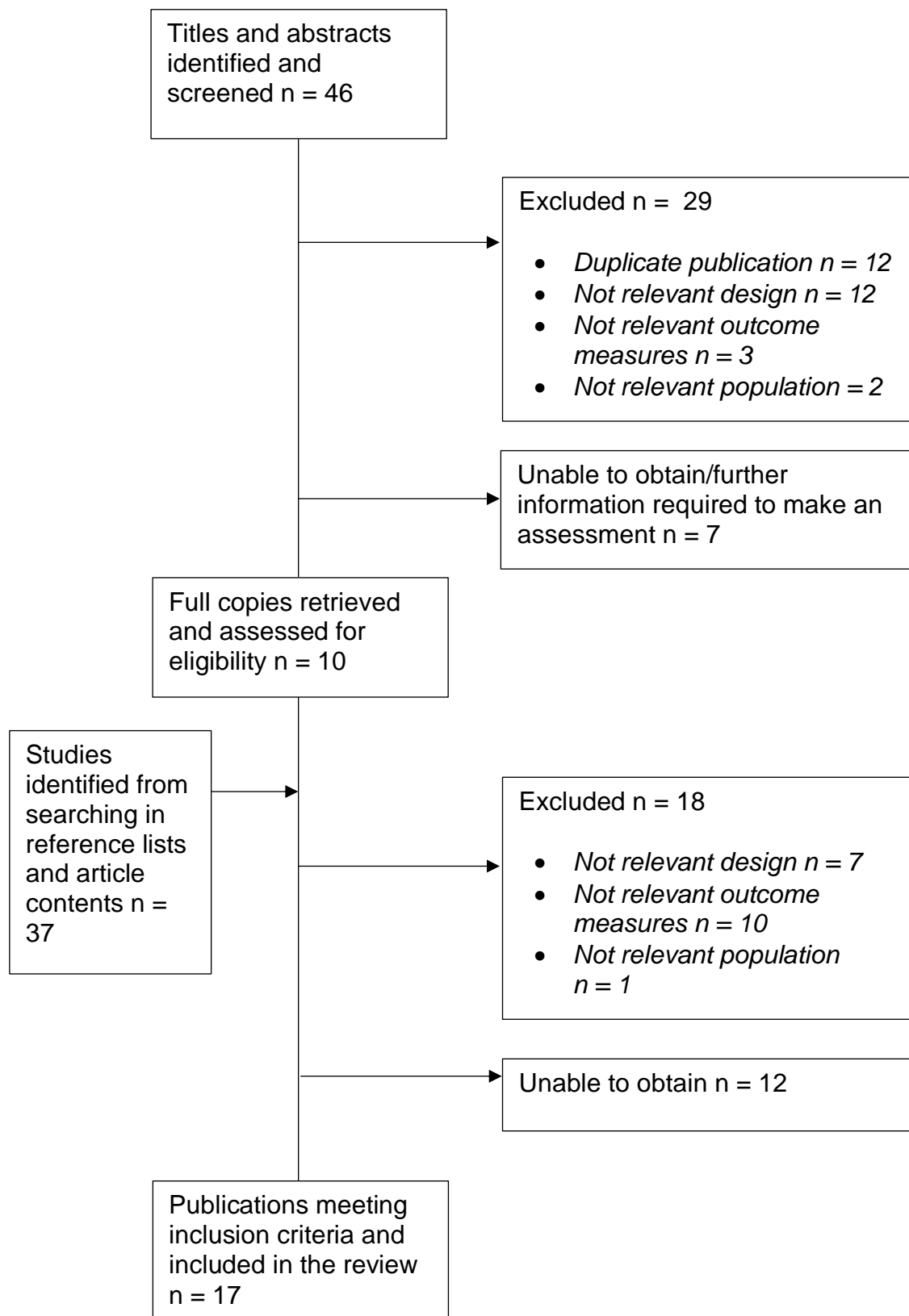


Figure 1. PRISMA Diagram illustrating the search and study selection process

Table 1.

Quality Assessment of the studies included in the systematic review.

Study	Sample	Confounding factors		Measurements		Statistical analysis		
	Adequately described	Representative of target population	Identified important	Accounted for (where possible)	Standardised	Meaningful to research question	Adequately described and reported	Appropriate for study design
Attawong & Kovindha (2005)	P _a	Y	P	P	Y	Y	Y	P _b
Bat-Chava (1994)	Y _a	Y	Y	Y	P _c	P _d	Y	Y
Bogart (2014)	Y	Y	Y	Y	Y	Y	Y	Y
Bogart (2015)	P _e	P _f	Y	Y	Y	Y	Y	Y
Boone, Roessler, & Cooper (1978)	P _g	P _f	Y	N _h	Y	Y	P	Y
Chalk (2016)	N _{ei}	P _{fj}	P	N _h	P _{cd}	N _d	P	Y
Ditchman et al. (2017)	Y	P _f	Y	P _h	Y	Y	Y	Y
Ferrin, Chan, Chronister, & Chiu (2011)	P _a	P	P	P _h	Y	Y	Y	Y
Jiao, Heyne, & Lam (2012)	N _{ag}	U	Y	P	Y	Y	Y	Y

Study	Sample		Confounding factors		Measurements		Statistical analysis	
	Adequately described	Representative of target population	Identified important	Accounted for (where possible)	Standardised	Meaningful to research question	Adequately described and reported	Appropriate for study design
Kim, Schilling, Kim, & Han (2016)	P _a	P	Y	P _k	P _c	P	Y	Y
Li & Moore (1998)	Y	Y	Y	Y	P _c	Y	Y	Y
Nario-Redmond et al. (2013)	Y	P _f	Y	P _h	Y	Y	Y	Y
Nichols et al. (2011)	P _a	P	Y	Y _l	P _m	P	P	Y
Olney et al. (2004)	P _{ij}	P	Y	P	N _d	P _d	N	U
Smedema et al. (2010)	Y	Y	Y	Y	Y	Y	P	U
Townend, Tinson, Kwan, & Sharpe (2010)	N _a	P	P _n	P	Y	Y	Y	Y
Zhang (2013)	P _a	P	Y	Y	Y	Y	Y	Y

Note. Y = Yes (item adequately addressed); N = No (item not adequately addressed); P = Partially (item partially addressed); U = Unclear (insufficient information is provided). _a Ethnicity of participants is not reported. _b Assumptions of statistical procedure were violated (collinearity).

_c A mixture of standardised and unstandardized measures used. _d Single item measures included. _e Publication cited for further description. _f Compared to target population, one or more demographic characteristic is overrepresented. _g Gender not reported. _h Disproportionate features of sample not accounted for in analyses. _i Participants' disabling conditions/impairments are not reported. _j Unclear whether participants have a diagnosed disabling condition.

_k Receipt of assistance to complete measures was not recorded or accounted for in analyses. _l Analyses of gender may be underpowered due to small N.

_m Translated version of standardised measure used that is yet to be validated. _n Timeline for collection of data is unclear i.e. when initial data collection took place in relation to disability onset.

The results of the quality assessment are shown in Table 1. Overall methodological quality of included studies was good. The descriptions and representativeness of samples was the area of poorest quality. Five out of the 17 studies reported adequate descriptions of their samples. Notably, seven studies did not report the ethnicity of participants, two directed the reader to previous publications for further details and two did not report participants' specific disability. Fourteen out of the 17 studies described samples that were representative or partially representative of their target populations. Five reported sample characteristics that were disproportionate to their target population (e.g. Bogart (2015) notes that women were slightly underrepresented compared to multiple-sclerosis population norms).

Thirteen out of 17 studies identified important confounding factors (e.g. sampling methods, representativeness of sample, impact of condition/impairment on reporting, validity and reliability of measures). Seven studies accounted for and eight partially accounted for confounding factors where possible. A number of studies included exclusion criteria (e.g. time since onset of impairment and presence of existing psychiatric condition), statistical controls (e.g. for demographic characteristics and functional impairment) and adjustments for accessibility (e.g. assistance with completing measures) to reduce the impact of confounding factors.

Eleven studies used standardised and six studies used partially standardised measures. Of note, two studies used single-item measures to assess disability identity (Chalk, 2016; Olney et al., 2004). The measures were

meaningful to the research questions in 12 studies and partially meaningful in 3 studies.

The statistical analyses were adequately described in 12 studies and partially adequately described in 4 studies. Quality was reduced by a lack of description or detail of the statistical procedure prior to presenting the results. Fourteen of the studies used appropriate analyses for the research design. For two studies it was unclear whether the procedures were appropriate given the limited descriptions provided.

Table 2.

Study characteristics and results of the studies included in the systematic review.

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
	<i>Design, data collection method</i>	<i>N, gender, disability, age, recruitment source, country of origin</i>	<i>Disability identity, wellbeing and additional measures included in relevant analyses</i>	
Attawong & Kovindha (2005)	Cross sectional, correlational design.	61 (47 male, 14 female) spinal cord injury patients.	Acceptance of Disability Scale (Linkowski, 1971) (Translated into Thai)	Acceptance of disability was negatively correlated with symptoms of depression ($r = -.488, p < .01$) and anxiety ($r = -.456, p < .01$).
	Data collected via self-report questionnaires.	Mean age 36.6 years (SD = 13.3). Recruited at outpatient clinic and rehabilitation ward in Thailand.	The Thai Hospital Anxiety and Depression Scale (Nilchaikovit, 1996)	
Bat-Chava (1994)	Cross sectional, correlational design.	267 deaf adults (117 males, 150 females).	Disability identification was assessed by (a) percentage of deaf friends (b) identification with the deaf community. Answers coded on a 3-point scale.	Disability identification was positively correlated with self-esteem ($r = .18, p < .01$). Disability identity ($\beta = .24, p < .001$) moderated the relationship between school deafness orientation and self-esteem (protective effect) ($R^2 = .11, F(3, 246) = 10.18, p < .001$).
	Data collected via self-report questionnaire (available in American Sign Language).	Mean age 42.9 years (SD not reported) (range = 16 - 87). Recruited via social and political groups for deaf people in the U.S.	Three items from Rosenberg Self-Esteem Scale (Rosenberg, 1979)	

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
			School deafness orientation measured by two items: type of school and method of communication used.	
			In-group comparisons measured by one item: the extent economic comparisons were made in relation to hearing or deaf people.	
Bogart (2014)	Cross sectional, correlational design. Data collected via an online questionnaire.	226 (107 male, 119 female) adults with congenital and acquired mobility disabilities. Mean age 36.96 years (SD = 12.69) (those with congenital disabilities) and 57.12 years (SD = 11.73) (acquired disabilities). Recruited via a range of disability organisations in the U.S.	Personal Identity Scale (Hahn & Belt, 2004) used to measure disability identity Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985) Rosenberg Self-Esteem Scale (Rosenberg, 1965)	Disability identity positively correlated with satisfaction with life ($r = .54, p < .01$) and self-esteem ($r = .47, p < .01$). Disability identity a significant predictor of satisfaction with life (above and beyond self-esteem and demographic variables) ($\beta = 0.22, p < .01$). Disability identity mediated the differences between people with congenital and acquired disabilities in satisfaction with life scores ($b = -1.27$).
Bogart (2015)	Cross sectional, correlational design.	106 (58 male, 48 female) multiple sclerosis patients.	Disability Personal Identity Scale (Hahn & Belt, 2004)	Disability identity was a unique predictor of depression ($\beta = -0.31, p < .01, R^2 \text{ change} = 0.09$) and anxiety ($\beta = -0.21, p < .05, R^2 \text{ change} = 0.04$). Disability

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
	Data collected via an online questionnaire.	Mean age 58.30 years (SD = 8.85). Recruited via multiple sclerosis organisations in the U.S.	The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)	identity was a stronger predictor of depression than activities of daily living ($\beta = -0.26, p < .01$).
Boone et al. (1978)	Cross sectional, correlational design. Data collected via a paper questionnaire.	48 (33 male, 15 female) participants with a range of physically disabilities. Age range 18 – 22 years (mean and SD not reported). Recruited via rehabilitation centre in U.S.	The Acceptance of Disability Scale (Linkowski, 1971) Manifest Anxiety Scale (Taylor, 1953)	Anxiety and acceptance of disability had a curvilinear relationship. Anxiety and anxiety squared significantly predicted acceptance of disability ($F(2,45) = 11.66, p < .001$) ($R^2 = .34$).
Chalk (2016)	Cross sectional, correlational and differential design. Data collected via an online questionnaire.	1,353 (541 males, 812 females) university students. Mean age 21.23 years (SD = 3.21). Recruited via multiple universities across the U.S.	Disability self-categorization (identity) assessed by one item: whether they were best described as “disabled” or “not disabled.” Experience of a disabling impairment assessed by one item: identification with experience of any disabling impairments in six categories (physical, sensory, learning, psychiatric, chronic health, or other).	Participants who self-categorized as disabled did not significantly differ from those who did not self-categorize as disabled (with or without a disabling impairment) on self-esteem or perceived esteem (statistics not reported). The positive relationship between mindfulness and self-esteem was significantly higher in those who self-categorized as disabled $z(39) = .60$, than in those without impairments, $z(894) = .20, z = 2.42, p = .02$, Cohen's $q = 40$; or those with impairments who did not self-categorize as disabled, $z(129) = .23, z = 2.00, p =$

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
			Self-esteem measured by a combination of the Single Item Self-Esteem Scale (Robins, Hendin, & Trzesniewski, 2001) and the 5-item Satisfaction with Life Scale (Diener et al., 1985)	.04, Cohen's $q = .37$.
			The Perceived Esteem Inventory (Hermann, Lucas & Friedrich, 2008)	
Ditchman et al. (2017)	Cross sectional, correlational design. Data was collected via postal, online and self-administered questionnaires.	105 (58 male, 47 female) adults with brain injury. Mean age 50.19 years (SD = 12.96). Recruited via two brain injury support groups in U.S.	The Acceptance of Chronic Health Conditions Scale (Stuifbergen, Becker, Blozis, & Beal, 2008) Satisfaction with Life Scale (Diener et al., 1985) Symptom severity: Problem Checklist (PCL; Kay, Cavallo, Ezrachi, & Vavagiakis, 1995). Self-Efficacy Scale (Sherer & Maddux, 1982)	Disability acceptance highly positively correlated with life satisfaction ($r = .58$, $p < .001$). Together, disability acceptance ($\beta = 0.43$, $p < .001$) and social self-efficacy ($\beta = 0.38$, $p < .001$) fully mediated the relationship between symptom severity and life satisfaction ($R^2 = 0.47$, $F(3, 101) = 29.62$, $p < .001$).

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
Ferrin et al. (2011)	Cross sectional, differential design. Data collected via self-administered questionnaire.	161 (124 males, 37 females) persons with spinal cord injury. Mean age 46.9 years (SD 15.5). Recruited through the Canadian Paraplegic Association.	Multidimensional Acceptance of Loss Scale (Ferrin et al., 2011) World Health Organization Quality of Life – Brief Version (Group, 1998) Rosenberg Self-Esteem Scale (Rosenberg, 1965)	Participants classified as having high disability acceptance had significantly higher self-esteem than those with medium and low disability acceptance. Participants with a high disability acceptance style had significantly higher quality life in the domains of Physical capacity and Social relationships than medium or low acceptance style. Individuals who have a high or medium versus low disability acceptance style have a higher quality of life in the Psychological domain. Finally, individuals who have a high versus low disability acceptance style have a higher quality of life in the Environment domain. Statistics are not reported for these analyses. (Statistics were not reported for any of the relevant analyses).
Jiao et al. (2012)	Cross sectional, correlational design. Data collected via a face-to-face and telephone interviews.	100 (gender not reported) individuals with spinal cord injury. Mean age 37.68 years (SD = 11.77). Recruited via an outpatient rehabilitation centre in China.	Acceptance of Disability Scale (Linkowski, 1971) (Chinese version) Center for Epidemiological Studies Short Depression Scale (Andresen, Malmgren, Carter, & Patrick, 1994) (Chinese version)	Participants classified as depressed reported significantly lower levels of acceptance of disability than those classified as non-depressed ($t = 4.59, p < .01$). Acceptance of disability was negatively correlated with depressive symptoms ($r = -.57, p < .01$). Depression mediated the relationship between perceived social support and acceptance of disability (the standardised indirect effect was $(-.450) (-.562) = .014, p < .01$).

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
			Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988) (Chinese version).	
Kim et al. (2016)	Cross sectional, correlational design. Data collected via a face-to-face survey method with Computer-Assisted Personal Interviewing	182 adults (104 male, 78 female) with Learning Disabilities (IQ range = 50 - 70). Mean age 40.6 (SD = 12.4). Data gathered from the 2011 Korean Panel Survey of Employment for the Disabled.	Acceptance of Disability: Nine items from The Disability Acceptance Scale (Kaiser, Wingate, Freeman & Chandler, 1987), and three items from The Self-Concept and Acceptance Test for People with Disabilities (Kang, Park & Gu, 2008). Life satisfaction measured by four items from the Panel Survey of Employment for the Disabled (Employment Development Institute, 2012).	Life satisfaction positively correlated with disability acceptance ($r = .516, p < .01$). Disability acceptance was a statistically significant predictor of life satisfaction ($\beta = .354, p < .001$) alongside, age, leisure satisfaction, family and friend relationships ($R^2 = .48$)
Li & Moore (1998)	Cross sectional, correlational design. Data collected via postal surveys.	1,266 adults (616 male, 650 female) with a range of physical and learning disabilities and mental illnesses. Median age 33 years (mean and SD not reported)	Acceptance of Disability Scale (Linkowski, 1971) Self-esteem measured by an adapted version of the Self Rating Form, (Knight, Holcomb, & Simpson, 1993; Simpson, Knight, & Ray, 1993)	Disability acceptance positively correlated with self-esteem ($r = .531, p < .001$). Self-esteem (alongside perceived discrimination and emotional support) remained a significant predictor of disability acceptance ($\beta = .435, p < .001$) when psychosocial factors were held constant ($R^2 = .338$). In the final model, self-esteem was the strongest predictor of

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
		Participants were randomly sampled from multiple rehabilitation service databases in the U.S.	Perceived discrimination was measured by an adapted version of belief of Devaluation or Discrimination Scale (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989)	disability acceptance ($R_2 = .441$) ($\beta = .360$, $p < .001$), followed by perceived discrimination, chronic pain, age, disability onset, and multiple disabilities.
			Emotional support was measured by two items created by the authors.	
Nario-Redmond et al. (2013)	Cross sectional, correlational design. Data collected through face-to-face, self-administered and online surveys.	Community sample: 93 adults (44 men, 49 women) with physical, sensory, learning and psychiatric disabilities. Mean age 40.25 years (SD = 13.18). Recruited via community based disability services in the U.S. Online sample: 256 adults (95 males, 161 females) with 'disabling conditions'.	Disability Identification (Nario-Redmond et al., 2013) Collective Self-Esteem Scale (Luhtanen & Crocker, 1992) Rosenberg Self-Esteem Scale (Rosenberg, 1965)	Across the community and online samples, disability identification was positively correlated with personal ($r = .27$, $r = .17$, $p < .01$) and collective self-esteem ($r = .52$, $r = .53$, $p < .01$). Disability identification was the strongest predictor of collective self-esteem in both the community ($R_2 = .35$) ($\beta = .38$, $p < .001$) and online sample ($R_2 = .36$) ($\beta = .60$, $p < .001$). Disability identity was a significant predictor of personal self-esteem in both samples, however it did not remain significant when coping strategies, disability visibility and proportion of life disabled were entered in the models.

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
		Mean age 45.87 years, (SD = 12.61). Participants were recruited via web-based disability communities.		
Nicholls et al. (2011)	Cross sectional, correlational design. Data collected through face-to-face interviews.	40 adults (37 male, 3 female) with spinal cord injury. Mean age 34.75 years (SD = 11.04). Recruited via a disabilities foundation in Columbia, South America. Patients who had accessed spinal cord injury services were contacted.	Acceptance of Disability Scale (Linkowski, 1971) translated into Spanish Depression measured using the Patient Health Questionnaire-9 (Kroenke, Spitzer & Williams, 2001)	Depression negatively correlated with disability acceptance ($r = .479, p = .002$). Depression (alongside gender) was a significant predictor of disability acceptance ($\beta = -2.47, p = .006, R^2 = .37$).
Olney et al. (2004)	Cross sectional, differential and correlational design. Data collected through self-administered surveys.	145,007 adults (gender not reported) of the general population. Mean age not reported. Recruited via a U.S. general population survey.	Disability identity measured by two items from the National Health Interview Survey (National Center for Health Statistics, 1998); "do you consider yourself to have a disability?" and "do other people think [you] have a disability?"	Those who rejected a disability identity (i.e. those that did not self-report as disabled but reported that others would identify them as disabled) reported significantly lower rates of mental health problems than those who identified as being disabled ($X^2 (3, N = \text{not reported}) = 73.3, p < .05$). Rejecting a disability identity was associated with fewer mental health problems, even when controlling for demographic characteristics, health

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
			Mental health problems measured by self-report on the National Health Interview Survey (National Center for Health Statistics, 1998) (specific questions not reported).	status and disability severity ($\beta = 0.69$, $p < .001$) (R^2 = not reported).
Smedema et al. (2010)	Cross sectional, correlational design. Data collected through postal and online surveys.	242 adults (160 males, 82 females) with spinal cord injury. Mean age 44.6 years (SD = 13.2). Recruited via a U.S. brain and spinal cord injury services.	The acceptance subscale of the Spinal Cord Lesion-Related Coping Scale (Elfstrom, Kreuter, Ryden, Persson, & Sullivan, 2002) The Satisfaction with Life Scale (Diener et al., 1985) The Rosenberg Self-Esteem Scale (Rosenberg, 1965)	Acceptance of disability positively correlated to quality of life, ($r = .149$, $p .05$) satisfaction with life, ($r = .405$, $p < .01$) self-esteem ($r = .656$, $p < .01$).
Townend et al. (2010)	A prospective, cross sectional, mixed design (quantitative and qualitative; correlational and differential design) was used. Structured face-to-face interviews were	89 adults (53 male, 36 female) who had experienced a stroke. Mean age 70.13 years (SD = 11.29). Recruited via an NHS general hospital in the U.K. (81 participants were followed up nine months,	Acceptance of Illness Questionnaire (Felton & Revenson, 1984) adapted to stroke-related-disability The Structured Clinical Interview for the fourth edition of the Diagnostic and Statistical Manual of the American Psychiatric Association	Non-acceptance of disability remained positively correlated with depressive disorder after controlling for age, gender, original stroke severity and current disability at one month ($r = .46$, $p = .001$) (OR = 1.270, $p = .001$) and nine months (OR = 1.457, $p = .001$). Non-acceptance of disability measured at one month independently predicted depressive disorder at nine months (OR = 1.190, $p = .007$). Participants with depression

Author, publication date	Study Characteristics	Participant characteristics	Measures	Results
	administered at 1 and 9 months.	gender and age data not provided)	(American Psychiatric Association, 1994) The National Institute for Health Stroke Severity Scale (Wade, 1992)	reported significantly higher non-acceptance than non-depressed participants ($t = 4.88, p = .001$)
Zhang (2013)	Cross sectional, correlational design. Data collected through self-administered questionnaires.	111 adults (70 males, 41 females) who had undergone colostomy surgery. Mean age 58.93 years (SD = 12.21). Recruited via four hospitals in Guangzhou, China.	Acceptance of Disability Scale (Linkowski, 1971) The European Organization for Research and Treatment of Cancer, Quality of Life for Cancer Patients Questionnaire (Ringdal & Ringdal, 1993) The European Organization for Research and Treatment of Cancer, Colorectal Cancer-Specific Quality of Life Questionnaire (Sprangers, te Velde & Aaronson, 1999) Social Relational Quality Scale (Hou, Lam, Law, Fu & Fielding, 2009)	Disability acceptance significantly positively associated with quality of life functioning domain scores, including physical ($r = .43, p < .05$), role ($r = .44, p < .05$), emotional ($r = .42, p < .05$), cognitive ($r = .46, p < .05$) and social functioning ($r = .43, p < .05$).

Study Characteristics

Characteristics and results of the 17 included studies are presented in Table 2. Studies were published between 1978 and 2017. Research was conducted in a range of countries, including the U.S. (10 studies), China (2), Canada, Korea, South America, Thailand and the U.K. All studies utilised a cross-sectional design, with 13 using correlational, three correlational and differential, one solely differential and one using a prospective mixed-methods design. Data was collected primarily through self-report questionnaires (13 studies) and four studies used face-to-face interviews. One study offered the questionnaire in American Sign Language format. Samples ranged from 40 to 145,007 participants (median = 161). Four studies sampled people with a range of disabilities (described as having physical (congenital and acquired), psychiatric and learning disabilities), four sampled spinal cord injury patients and two sampled general populations (where disability was self-reported). The remainder included brain injury patients, deaf adults, multiple sclerosis patients, paraplegics, stroke patients, people with learning disabilities and post-colostomy surgery patients. The studies varied in recruitment sources; seven utilised disability groups (e.g. charities, support groups and social-political groups), five utilised rehabilitation facilities (i.e. wards or clinics), two used general hospitals, two used population survey data and one recruited via a university.

Psychological wellbeing was assessed with five concepts and 15 measures; self-esteem (9 studies, 5 measures), quality of life (7 studies, 5 measures), depression (4 studies, 4 measures), anxiety (3 studies, 2 measures) and

'mental health problems' (1 study, 1 measure). The most frequently used measures included The Rosenberg Self-Esteem Scale (Rosenberg, 1979) (5 studies), the Satisfaction with Life Scale (Diener et al., 1985) (3 studies) and the Hospital Anxiety and Depression Scale (Nilchaikovit, 1996) (2 studies). Disability identity was assessed with three concepts and 10 measures; disability acceptance (11 studies, 5 measures), disability identity or self-categorisation (6 studies, 5 measures). The Acceptance of Disability Scale (Linkowski, 1971) was used most frequently (6 studies) followed by the Personal Identity Scale (Hahn & Belt, 2004) (2 studies). Four studies used unvalidated measures that were either developed by the authors or questions from general population surveys (2 of which included single-item responses).

Study findings

Measures of psychological wellbeing.

Depression.

Four studies presented significant negative correlations between measures of disability identity/acceptance and depression ($r = -.46$ to $-.57$) (Attawong & Kovindha, 2005; Jiao et al., 2012; Nicholls et al., 2011; Townend et al., 2010). Two studies reported that participants classified as depressed showed significantly lower disability acceptance scores than participants classified as non-depressed (Jiao et al., 2012; Townend et al., 2010). One study found increases in disability identity was a unique predictor of lower depression scores (Bogart, 2015).

Anxiety.

One study found a significant negative correlation between a measure of disability acceptance and anxiety ($r = -.46$) (Attawong & Kovindha, 2005). Another study found increases in disability identity was a unique predictor of lower scores on the same measure of anxiety (HADS) (Bogart, 2015). One final study found another measure of anxiety (the Manifest Anxiety Scale) and disability acceptance had a curvilinear relationship (Boone et al., 1978).

Self-esteem.

Five studies reported significant positive correlations between measures of disability identity/acceptance and self-esteem ($r = .18$ to $.66$) (Bat-Chava, 1994; Bogart, 2014; Li & Moore, 1998; Nario-Redmond et al., 2013; Smedema et al., 2010). One study found that those who self-categorized as disabled did not significantly differ in self-esteem scores to those not identifying as disabled (Chalk, 2016). Conversely, one study found that participants classified with high disability acceptance scores had higher self-esteem scores than those with low or medium disability identity (Ferrin et al., 2011).

Quality of life.

Five studies reported significant positive correlations between measures of disability identity/acceptance and quality of life ($r = .35$ to $.58$) (Bogart, 2014; Ditchman et al., 2017; Kim et al., 2016; Smedema et al., 2010; Zhang, 2013).

One study found participants with high disability acceptance had significantly higher scores in multiple quality of life domains compared to those with medium and low disability acceptance (Ferrin et al., 2011).

Mental health problems.

One study found those who rejected a disability identity demonstrated significantly lower rates of mental health problems and rejecting a disability identity was associated with fewer mental health problems (Olney et al., 2004).

Discussion

This review systematically examined quantitative research investigating the relationship between disability identity and psychological wellbeing in adults. A total of 17 studies from the initial database and citation search met inclusion criteria. The included studies exhibited considerable variability in their designs, populations sampled and operational definitions of both disability identity and psychological wellbeing. Despite these inconsistencies, the combined results indicated that generally measures of disability identity positively correlated with measures that indicate higher psychological wellbeing (self-esteem, quality of life and satisfaction with life) and negatively correlated with measures that indicate poorer psychological wellbeing (depression and anxiety). Similarly, participants categorized as having higher disability identity scores demonstrated higher psychological wellbeing scores (quality of life) and participants with lower psychological wellbeing (higher depression scores) demonstrated lower disability identity scores. This would suggest that greater identification with being a disabled person, social contact with disabled people and non-devaluing values about disability are associated with greater psychological wellbeing.

Given that the majority of the designs included were cross-sectional, correlational and/or differential, neither causation nor the direction of the relationship between disability identity and psychological wellbeing can be inferred. It may be that one's disability identity impacts on one's psychological

wellbeing or vice-versa, however the current available literature was not able to infer this.

Methodological Factors

Compared to the qualitative and quantitative findings outlined previously (e.g. Barga, 1996; Fernández et al., 2012; Hull et al., 2017; Lynch & Gussel, 1996; Olney et al., 2004; Olney & Kim, 2001; Spiegel et al., 2015), the reviewed studies present more consistent findings of the relationship between disability identity and wellbeing. A number of factors were hypothesised to impact on the relationship between disability identity and wellbeing, potentially accounting for the variability previously described, which will now be considered in light of the reviewed data.

Olney et al. (2004) suggested that amalgamating studies of adults and children may have generated inconsistency in the results, as the relationship between disability identity and wellbeing may exhibit greater variability in childhood (Erikson, 1968). While the present findings cannot comment on the relationship in children, the results indicate a consistent relationship between disability identity and wellbeing is found when focusing on quantitative studies of adults where disability identity is operationalised. To the author's knowledge the only available data for children utilises qualitative methods (Barga, 1996; Lynch & Gussel, 1996). These studies found that efforts to "pass" as non-disabled (consistent with rejecting a disabled identity) was linked with stress and tension whereas others linked disclosures of disabilities (consistent with embracing disabled identities) with greater discrimination. It

may be that if quantitative methods were used, where disability identity and wellbeing are operationalised, similar consistency would be observed within a child and adolescent population.

It was also highlighted that wellbeing was defined and measured by several concepts (Olney et al., 2004). It was suggested that different relationships may exist between different measures of wellbeing and disability identity. This was not supported by the results of the current systematic review, which showed a largely consistent positive relationship between disability identity and different measures of wellbeing.

It was also suggested that the relationship between disability identity and wellbeing may have varied by disability or disability-specific factors (e.g. congenital versus acquired, nature of impairment), accounting for some of the discrepancy in the earlier findings. While an extensive range of disabled populations were not sampled across the reviewed studies (spinal cord injury, multiple sclerosis, Learning Disability, stroke, brain injury, deafness, acquired and congenital mobility disabilities) there was a largely consistent positive relationship between disability identity and wellbeing across the sampled disabilities. This would suggest that the positive relationship between disability identity and wellbeing does not vary by disability, however it will be important for future research to explore a greater range of disabled populations to investigate this further.

In terms of the magnitude of the relationship between disability identity and wellbeing across the different disabilities sampled, where described, medium to large effect sizes were generally consistently reported (i.e. the magnitude of the relationship did not differ amongst disabilities). There were two exceptions to this; Bat-Chava (1994) reported a small to medium effect size ($r = .18$) in a sample of deaf adults and Smedema et al. (2013) reported one small effect size ($r = .14$) in a sample of spinal cord injury patients. No other studies sampled deaf populations and six other analyses with spinal cord injury patients demonstrated medium to large effect sizes (Attawong & Kovindha, 2005; Nicholls et al., 2011; Jiao et al., 2012). Consequently, without replication of these findings it is difficult to conclude that the magnitude of the relationship differs amongst these specific populations. As a whole, the findings indicate the magnitude of the relationship between disability identity and wellbeing does not vary by disability.

Few studies explored the impact of disability-specific factors on the relationship between disability identity and wellbeing, making it difficult to investigate this across the reviewed papers, as this review had intended. One study found that disability identity moderated the differences in wellbeing between congenital and acquired disabilities (Bogart, 2014) suggesting that disability-specific factors may impact on the relationship between disability identity and wellbeing. Multiple studies also identified factors that impacted on disability identity and/or wellbeing separately such as chronicity of disability, comorbid chronic pain, symptom severity, number of disabilities and activities of daily living (Attawong & Kovindha, 2005; Bogart, 2014; Bat-Chava, 1994;

Ditchman et al., 2017). Together the results suggest that the magnitude of the relationship between disability identity and wellbeing may vary by disability specific factors (such as chronicity of disability or symptom severity).

Lastly, it was noted that the way disability identity is measured could affect the relationship between disability identity and wellbeing. The methods used to measure disability identity appears to be a consistent difference between the papers that demonstrated discrepant findings (Barga, 1996; Fernández et al., 2012; Hull et al., 2017; Lynch & Gussel, 1996; Olney & Kim, 2001; Spiegel et al., 2015) and the reviewed studies that exhibited consistent findings. The reviewed papers utilised measures of disability identity (most of which were standardised), as opposed to behavioural proxies of disability identity (e.g. disability disclosure, community integration and impairment reducing procedures) featured in the studies outlined in the introduction. The present results could indicate that these proxies do not constitute valid or reliable indicators of the full concept of disability identity, however direct comparisons between the measures are required to assess this hypothesis. Equally, the results may support the hypothesis that different aspects of disability identity relate differently to wellbeing (i.e. social integration versus claiming status). However, again this requires direct comparisons between the measures to assess this hypothesis.

Anomalous results

There were two notable exceptions to the overall trend in the results; where participants who identified as disabled demonstrated equal self-esteem

scores (Chalk, 2016) and reported greater mental health problems (Olney et al., 2004) compared to those who did not identify as disabled. These studies featured the largest sample sizes of the included studies (using general population and undergraduate samples) and utilised single-item measures of disability identity (e.g. “do you consider yourself to have a disability?”).

Whereas the majority of other studies had smaller samples, recruited via disability organisations (e.g. charities, support groups and rehabilitation facilitates) and generally used standardised measures of disability identity or acceptance. The differences in both the findings and methodologies of these papers could be interpreted in a number of ways.

Large general and undergraduate populations could constitute more representative samples of disabled people than smaller samples recruited via disability organisations, strengthening the weight of these incongruent results. Additionally, larger samples may encompass a greater range of experiences increasing the generalisability of these findings. Sampling via disability organisations may present a significant confounding factor, as disabled people who are connected to disability organisations may have greater social support than disconnected disabled people (Boynton & Chang, 1994; Obst & Jana, 2010). Social support is linked with greater disability identity and psychological wellbeing (Li & Moore, 1998; Jiao et al., 2012; Obst & Jana, 2010). Therefore, additional social support associated with disability organisation affiliation may account for the positive relationship between disability identity and psychological wellbeing demonstrated in the majority of the reviewed papers. This would lend support to the results from wider

populations and potentially undermine the results of the majority of studies reviewed.

However, a potential limitation of sampling from general populations is that disability status (i.e. presence of a disabling condition) is self-reported rather than verified through medical records or contact with disability services. In the two studies described (Chalk, 2016; Olney et al., 2004), participants' disabling conditions were not stated and it was unclear if they were reported by participants. This makes it difficult to verify participants' disability status and evaluate which conditions the results may apply to.

Similarly, single-item measures of disability identity may be problematic. Sauro (2018) cautions that single-item measures may lack construct validity and reliability. As outlined previously, disability identity refers to both claiming disability status, connection to disabled people and viewing disability as non-devaluing (Dunn, 2014; Shakespear, 1996; Wright, 1960; 1983). The single-item measures of disability identity included only assessed claiming disability status, (i.e. "do you consider yourself to have a disability?") potentially encompassing similar difficulties to the proxy measures discussed. Further, one may question the extent to which these single-items measure disability identity at all, as they may be considered to refer to a factual disclosure of impairment rather the extent to which disability is accepted as part of one's identity. Accordingly, the use of population data and single-item measures of disability identity appears to limit the generalisability and validity of the results.

As a result, the most valid understanding appears to be from the majority of studies which sampled via disability organisations and utilised standardised measures of disability identity, finding greater disability identity related to greater wellbeing.

Nonetheless, while studies using single-item measures may not adequately assess the concept of disability identity, alongside the results using standardised disability identity measures, the results could indicate a nuanced understanding of disability identity. They could indicate that claiming disability status alone (indicated by single-item measures) is not linked with greater psychological wellbeing, but that connecting with disabled people and holding non-devaluing values (which the standardised measures typically interrogate) are key to the association with greater psychological wellbeing. This hypothesis could be assessed by comparing the ways that factors of standardised measures (e.g. claiming disability status) and the full measures relate to wellbeing.

Disability Acceptance Theory

The overall trend in the results could be understood through Disability Acceptance Theory (Wright, 1960; 1983). As outlined, the theory proposes that value changes involved in disability acceptance enhances wellbeing by prompting coping strategies, positive identity formation and future goals (DeLoach & Greer, 1981; Livneh, 2001; Livneh & Antonak, 2005; Wright, 1960; 1983). It could be interpreted that the relatively consistent positive relationship

between disability identity and wellbeing found, relates to the value changes associated with accepting oneself as disabled.

However, there are a number of difficulties with applying this theory to the results. Firstly, measures of disability acceptance (which interrogate the value changes described in Disability Acceptance Theory) were only used in a proportion of the sampled studies. Consequently, it is unclear whether such values related to wellbeing in studies where they were not measured (i.e. where measures of disability identity were used instead of disability acceptance).

Secondly, the samples where disability acceptance measures were used, exclusively sampled participants with acquired disabilities (Attawong & Kovindha, 2005; Boone et al., 1978; Ditchman et al., 2017; Ferrin et al., 2011; Jiao et al., 2012; Li & Moore, 1998; Nicholls et al., 2011; Smedema et al., 2010; Townend et al., 2011) with the exception of Kim et al. (2016) who sampled adults with Learning Disabilities. Consequently, it is difficult to evaluate to what extent the value changes proposed by the Disability Acceptance Theory is applicable to people with congenital disabilities (Keaney & Gluekauf, 1993).

Lastly, only one study which measured disability acceptance used a prospective design (Townend et al., 2010). While the results were supportive of the Disability Acceptance Theory (showing non-acceptance at one month predicted depressive disorder at nine months) (Townend et al., 2010), further

replication using similar prospective designs is required to demonstrate the role of value change in the relationship between disability identity and wellbeing.

Social Identity Theory

The results may also be interpreted through SIT (Tajfel & Turner, 1979). As discussed, the theory proposes that members of stigmatised groups protect their wellbeing through individualistic or collective strategies (Tajfel & Turner, 1979). Collective strategies involve embracing one's stigmatised identity, seeking within-group contact and advocating for one's group (Nario-Redmond et al., 2013). Measures of disability identity and acceptance include multiple features of collective strategies, including claiming disability status, connection to disabled people and non-devaluing views of disability (Ferrin et al., 2011; Linkowski, 1971). Accordingly, the positive relationship between disability identity and wellbeing may relate to protective collective strategy processes, such as the promotion of favourable within-group comparisons, attribution of discrimination to out-group prejudice and devaluing group "weaknesses" (Crocker & Major, 1989; Tajfel & Turner, 1979).

However, a difficulty with applying SIT to the results is that the hypothesised strategies and protective processes are only investigated in one of the reviewed studies. Nario-Redmond et al. (2013) found that greater disability identity related to collective strategy use, a greater willingness to participate in disability rights, value the disability experience and reject "overcoming" strategies. This finding could support SIT predictions that protective collective

strategy processes account for the relationship between disability identity and wellbeing. However, as the relationship between collective strategies, disability identity and wellbeing were not investigated, it is not possible to draw such conclusions.

Strengths and limitations of the data

Overall, the general pattern of results was largely consistent across somewhat disparate methodologies, contexts and samples. This is a strength of the data, as it enables some conclusions to be being drawn about the general nature of the relationship between disability identity and psychological wellbeing.

However, as outlined, the lack of prospective studies and consistent measures of SIT and Disability Acceptance Theory concepts make it difficult to infer the direction of the relationship and evaluate the potential mechanisms underlying it. Longitudinal research which operationalises Wright's (1983) value changes, SIT's collective and individualistic strategies (Crocker & Major, 1989; Tajfel & Turner, 1979) is needed with people with acquired and congenital disabilities to explore the relationship between disability identity and wellbeing over time and the potential role of these theorised processes.

The overall quality of the papers was good. However, the descriptions of samples constituted a relative weakness. Of significance, participant's disabilities were not always reported or adequately described (e.g. described vaguely such as "physical disability" or time since disability onset was omitted). This limitation makes it difficult to assess the generalisability of the results to particular conditions and evaluate the impact of disability specific

factors (e.g. time since onset) on the relationship between disability identity and wellbeing. It is therefore key that future research provides adequate descriptions of participants' disabilities and such factors.

In addition, many papers did not report participants' ethnicities and few considered the role of ethnicity in their analyses. Ethnicity, like disability, is a key context which individuals identify with that involves degrees of privilege and oppression (Howard & Renfrow, 2014). From a SIT perspective (Tajfel & Turner, 1979), the multiplicity of contexts which people belong to shapes their experiences, social identities and wellbeing. Accordingly, the interrelation between disability identity, ethnic identity and psychological wellbeing is of theoretical and practical significance that should not be neglected in future research.

Measures of disability identity and psychological wellbeing varied considerably. This finding, to some extent, appears to be a strength of the data where the nature and magnitude of the relationship between disability identity and wellbeing is shown to be relatively stable across a range of concepts and measures (except single-item measures of disability identity). However, the lack of replication utilising the same measures may warrant caution in the interpretation of the results. Accordingly, some replication using the same measures may strengthen the findings.

It is important to consider the reliability and validity of scales of disability identity and wellbeing utilised in the reviewed papers. The quality assessment

identified that the majority of measures utilised were standardised and meaningful to the research question, enabling one to assume that the results are based on valid and reliable concepts. As discussed, the use of single-item measures appears problematic both conceptually and in terms of their psychometric properties. Going forward, it is recommended that researchers utilise standardised disability identity measures such as the Disability Personal Identity Scale (Hahn & Belt, 2004) or The Acceptance of Disability Scale (Linkowski, 1971) to ensure valid and reliable assessment.

Strengths and Limitations of the Review Process

The review process has embodied several strengths, including utilising a clear and replicable search strategy, a second reviewer and quality assessment. Such features indicate a robust and reliable strategy (Boland et al., 2014).

The initial agreement between the two reviewers was moderate (Cohen's $k = 0.55$). This indicates that the reviewers' selection of papers was largely consistent with some differences, reducing the replicability of the review. As the same 46 papers were produced from both database searches, the moderate interrater-reliability could suggest that the inclusion and exclusion criteria were not defined in sufficient detail. Instances of initial disagreement were predominantly related to the exclusion of chronic pain studies. These studies utilised measures of pain acceptance as opposed to disability acceptance which the reviewers came to agree were different concepts and were not relevant to the review question (and subsequently excluded). When chronic pain articles were removed from inter-rater calculations, agreement

was very good (Cohen's $k = .86$). Subsequently, it is argued that should the exclusion criteria include pain acceptance measures (when in place of disability acceptance/identity), the review would show much greater replicability.

The use of a 'bespoke' quality assessment tool may have both strengths and limitations. As it was designed in the absence of a tool suitable for the mixed designs found in these studies, it is arguably more meaningful to the review data. Additionally, it was based on existing tools and their critiques (Boland et al., 2014) thus may overcome some of the limitations of existing tools (e.g. providing ratings for individual sections of studies as opposed to a single overall rating). However, as it was not feasible for the second reviewer to perform an additional quality assessment and the tool is unstandardized, the reliability and validity of the tool is unclear.

It is important to consider how the search strategy may have influenced the studies identified and resultant findings. For example, whilst unpublished studies were not excluded as a part of the strategy, there is potential for the results to be biased by those that are more likely to get published. Non-significant results (i.e. where no relationship between disability identity and wellbeing were found) and those that may run counter to culturally sanctioned ideas (Brown, Mehta, & Allison, 2017) may be less likely to be published. For example, Fernandez et al. (2012) note that disability pride is endorsed by most American disability organisations, given that such organisations may play a role in gatekeeping English speaking academic publications, findings

that do not promote disability identity may have been less likely to be published, influencing the results found. Similarly, where the results were limited to English language papers, the results may also be influenced by English-speaking cultures and less relevant to other cultures.

A greater number of papers were identified from the manual search (nine papers) than the original database search (eight). This is potentially problematic as the manual search constitutes a less systematic stage of the search process and could therefore undermine the replicability of the review. This pattern of paper identification may be explained by a number of factors. It could indicate that the search terms did not adequately capture the relevant concepts (i.e. missed papers during the database search stage). Upon comparing the key terms used across the two sets of identified papers, three terms (that were not included in the search) were found in four of the manually identified papers: “adaption” and “adjustment” for psychological wellbeing and “group identification” for disability identity. Inclusion of these terms may have led to a greater number of papers being identified, potentially limiting the results identified. Re-running the original search with these terms in May 2019 identified 11 additional papers (five from PsychInfo and six from Web of Science), however only one paper met inclusion criteria (which had already been identified and included in the review through the original manual searches stage). This would indicate that the terms were mostly adequate in capturing the relevant concepts and cannot account for the full number of papers identified during the manual search.

Some papers identified during the manual search may not have been identified by the original search as the relevant analyses were not the main focus of the study i.e. constituted post-hoc tests or part of disability acceptance measure validation studies (Ferrin et al., 2011; Smedema et al., 2010) and the terms would not be listed as the key topic or throughout the full paper. As a result, the discrepancy in number of studies identified at different stages is not entirely problematic, as manual searches are intended to identify articles such as these (Gough, Oliver & Thomas, 2012).

The difference may also be explained by the number of papers identified by the database search that were unavailable (five). These papers were published between 1979 and 1990. Had these papers been available and suitable for inclusion, there may have been a smaller discrepancy between the number of papers identified at the database versus manual search stage. The availability of these papers may also have also impacted on the findings of the review. Should the unavailable papers all present negative relationships between disability identity and wellbeing, the overall findings would be more mixed, although still largely presenting a positive relationship (over two thirds of the total papers). Accordingly, the unavailability of these papers is unlikely to have had a significant impact on the main findings of the review.

Lastly, it was not possible to obtain a total of 12 papers across the search process (i.e. including the five previously discussed). This presents similar limitations to those discussed above. Whilst multiple methods were used to obtain these papers (e.g. searching within the University Library Collection,

Google Scholar and Research Gate; contacting the original authors) Inter-Library Loans were not considered. Accordingly, the review may not have included a small number of articles that could have been relevant to the search criteria. It is recommended that any future replications make use of Inter-Library loans where possible to attempt to access these papers.

Implications

Many researchers have called for disability services to develop disabled people's sense of disability identity in order to enhance their psychological wellbeing (Bogart, 2014; Olkin, 2008). While the evidence suggests disability identity is positively related to wellbeing, this review has not identified evidence for a causal relationship between disability identity and wellbeing or for the efficacy of interventions that target disability identity. Therefore, such recommendations cannot be made. Research is needed that investigates the impact of interventions aimed at increasing disability identity and/or psychological wellbeing to better understand the direction of this relationship and the potential for these interventions.

Nonetheless, the evidence would suggest that encouraging the development of a disability identity, that includes developing connections with disabled people and adopting non-devaluing values (as opposed to simply categorising oneself as disabled) has potentially positive implications for wellbeing. Being part of a disability-based community or being amongst other disabled people may provide social support that mediates the relationship between disability identity and wellbeing (i.e. accounts for the positive correlation). As a result,

disabled people's wellbeing may equally benefit from access to such disability organisations.

Conclusion

The present study systematically reviewed the quantitative literature exploring the relationship between disability identity and wellbeing in adults.

Standardised measures of disability identity were positively associated with multiple measures of psychological wellbeing, across a range of disabled populations. The reviewed evidence would suggest that encouraging the development of a disability identity, that includes developing connections with disabled people and adopting non-devaluing values (as opposed to claiming disability status alone) could be beneficial to wellbeing.

Chapter III: Empirical Study:

Camouflaging in Autism: An Individualistic Strategy in Response to a Stigmatised Social Identity?

Abstract

Camouflaging refers to strategies autistic people may use to mask or minimise features of autism in order to “pass” as non-autistic. Research has shown autistic people relate camouflaging to experiencing poorer psychological wellbeing. The present study draws on Social Identity Theory to explore the relationship between camouflaging and wellbeing. It examines the theory that camouflaging represents an individualistic strategy in response to the stigmatised social status of autism. Three-hundred and two (184 female, 61 male and 56 non-binary identifying) autistic adults (mean age = 34.36) completed an online survey relating to their experiences of stigma, coping strategies, camouflaging and wellbeing. Regression analyses found increases in camouflaging were positively predicted by autism-related stigma, female gender, older age at diagnosis, individualistic and collective strategy use. A mediation analysis found autism-related stigma had a negative effect on wellbeing, which was mediated by camouflaging, suggesting stigma influences wellbeing through its effect on camouflaging. The findings indicate camouflaging bears likeness to an individualistic strategy in its positive relation to stigmatisation and lower wellbeing. However, it differs in its positive relation to collective strategy use, indicating it may co-occur with embracing autistic identity and community. The results reinforce recommendations for

clinicians to be aware of camouflaging and demonstrate the need for anti-autism-stigma interventions for the general population.

Introduction

Autistic people typically show differences in their social communication, sensitivity to sensory stimulation and focused nature of their interests (American Psychological Association; APA, 2013). A diagnosis of autism is made on the basis of the presence of such differences in a person's early development and current life, that relates to difficulties in everyday functioning (APA, 2013). Diagnosis may be made in childhood or adulthood, with diagnosis in adulthood often thought to relate to individuals camouflaging or masking their autistic traits (APA, 2013; Cook, Ogden, & Winstone, 2018)

Camouflaging has recently propelled into the focus of autism research, following the International Classification of Diseases' (ICD; Zeldovich, 2017) call for clinicians to be aware of masking behaviours when assessing autism. Camouflaging refers to strategies that function to mask or minimise features of autism and allow a person to "pass" as neurotypical in social situations (Hull et al., 2017). It can include conscious and unconscious attempts to hide behaviours associated with autism or social difference (e.g. self-stimulating behaviours, unusual or intense interests) and the use of explicit techniques to appear socially competent (e.g. rehearsing facial expressions, eye contact, body language and social scripts) (Bargiela, Steward & Mandy, 2016; Hull et al., 2017).

Camouflaging is of particular interest for the diagnosis of autism, as it is hypothesised to relate to the late and misdiagnosis of autism, particularly in

women (Hull et al., 2017; Lai et al., 2015). It is thought that camouflaging can result in autistic traits being missed by both referrers and assessing clinicians, obscuring opportunities for clinical diagnosis (Cook et al., 2018). Women are theorised to camouflage more, due to differences in their social abilities and the social pressures placed upon women, perhaps partially accounting for greater late and misdiagnoses in women (Cage & Troxell-Whitman, 2019; Cook et al., 2018; Lai et al., 2017). However, thus far the empirical research has provided mixed results in terms of gender differences in camouflaging to verify these theories (Cage, Di Monaco & Newell, 2018; Cage & Troxell-Whitman, 2019; Hull et al., 2017; Lai et al., 2017).

Camouflaging is also of great importance for understanding the clinical needs of autistic people. Qualitative research has repeatedly shown autistic people relate camouflaging to experiencing greater stress, anxiety, exhaustion and other mental health difficulties (Bargiela et al., 2016; Hull et al., 2017; Tierney, Burns & Kilbey, 2016). Further, a small number of quantitative studies have demonstrated that self-reported camouflaging is linked to lower psychological wellbeing and quality of life, and higher reports of depression, anxiety, stress and social anxiety (Cage & Troxell-Whitman, 2019; Cage et al., 2018; Hull et al., 2019).

Given the high lifetime prevalence of mental health difficulties in autistic people (estimated between 50 and 69%) (Buck et al., 2012; Hofvander et al., 2009; Lehnhardt et al., 2011), understanding behaviours that may negatively impact on psychological wellbeing is imperative. Identifying why autistic

people camouflage and how camouflaging relates to wellbeing may enable better support for autistic people, by potentially targeting the reasons autistic people camouflage or identifying ways of camouflaging that do not relate negatively to wellbeing.

Qualitative research exploring autistic people's experiences of camouflaging has pointed to a multitude of motivations for camouflaging and ways it may impact on wellbeing. Hull et al's. (2017) survey with 92 autistic adults identified that people were motivated by a desire to assimilate, connect with others and avoid exclusion and discrimination. Participants described being exhausted from the prolonged periods of self-control, concentration and discomfort involved in camouflaging as well as worrying about the effectiveness of ones' camouflaging attempts (Hull et al., 2017). Late-diagnosed autistic women have similarly associated camouflaging with a desire to "fit in" and "pretend to be normal" (Bargiela et al., 2016; Holliday-Willey, 2015). They have described the effort to consciously process and replicate others' behaviours as exhausting and confusing for their sense of identity (Bargiela et al., 2016). Interviews with ten autistic adolescent females revealed parallel themes of a desire to make friends and gain acceptance following experiences of rejection (Tierney et al., 2016). The girls described finding it stressful to hide their true emotions, feeling unsure of who they were and a pressure to conform to social norms (Tierney et al., 2016). Lastly, Cage and Troxell-Whitman's (2019) mixed-methods research with 262 autistic adults found that participants reported camouflaging in order to "pass" in the neurotypical world, avoid bullying and manage others' impressions of them.

As yet, only one study has attempted to integrate the many qualitative findings or present a theory that synthesises the motivations and consequences of camouflaging. Cage and Troxell-Whitman (2019) applied Disconnect Theory (Ragins, 2008) to explore the link between camouflaging and reduced wellbeing. They hypothesised that greater disconnection between the way one presents oneself across contexts (e.g. camouflaging in some settings and not others) may lead to identity fragmentation, stress, anxiety and depression (Bowen & Blackmon, 2003; Cage & Troxell-Whitman, 2019; Ragins 2008). Their findings partly supported the theory, where participants who camouflaged in some settings and not others (i.e. formal versus interpersonal settings) showed equivalent anxiety and stress symptoms to those who camouflaged highly in all settings (Cage & Troxell-Whitman, 2019). ‘Low camouflagers’ showed lower stress than both groups and lower anxiety than ‘high camouflagers’. These findings suggest intermittent camouflaging produces equal psychological strain as constant camouflaging. The authors suggest that the constant evaluation of whether to expose one’s autistic identity may provide an equivalent burden to constantly hiding features of one’s autistic identity.

Bottema-Beutel, Park and Kim (2018) describe this constant evaluation as a hyper-awareness during social situations where one is constantly managing autism-related stigma. Hatzenbuehler, Phelan and Link (2013) suggest that the long-term management of stigma depletes psychological resources, leading to difficulties regulating emotions, often cited as the core of mental

health difficulties (Linehan, 2014). Accordingly, one theory that may underpin many of the existing findings is that camouflaging represents a response to the stigmatisation of autism (Cage & Troxell-Whitman, 2019). Goffman (2009) defines stigma as the social discrediting of an attribute which causes individual(s) to feel unacceptable or 'othered'. Key motivations for camouflaging in the literature appear to centre around 'fitting in', gaining acceptance and avoiding exclusion (Hull et al., 2017; Cage et al., 2017; Cage & Troxell-Whitman, 2019), which seem to bear likeness to the experience of being stigmatised.

There is much evidence to suggest that autism is stigmatised throughout Western societies (Gates, 2019) and autism is increasingly understood as an identity-based minority disadvantaged by stigmatised social status (Botha & Frost, 2018). Autistic adults and children commonly report experiencing autism-related stigma (Beardon & Edmons, 2007; Botha & Frost, 2018; Cameron, 2014; Shtayermman, 2009). Neurotypical adults are found to hold stigmatising attitudes towards autistic people in multiple contexts and make more negative initial evaluations of autistic individuals (Brosnan & Mills, 2009; Sasson, Faso, Nugent, Lovell, Kennedy, & Grossman, 2017; Shcherbakov, 2016). Further, depictions of autism within media, legislation, research and even autism charities are found to stigmatise or promote the stigmatisation of autism (Nicolaidis, 2012; Gillespie et al., 2017; Holton et al., 2014). Consequently, the stigmatisation of autism appears widespread, indicating the utility of understanding autistic experiences through the impact of stigma (Botha & Frost, 2018).

Tajfel and Turner's (1979) Social Identity Theory (SIT) proposes that when a social identity³ is stigmatised (e.g. being autistic), people seek to regain a positive social identity through individualistic and collective strategies.

Individualistic strategies involve dissociating from one's group and attempting to join or "pass" into a higher status group (e.g. neurotypical people). These strategies seek to benefit the individual by achieving personal upward social mobility. In contrast, collective strategies aim to benefit the group status by positively re-defining or re-evaluating the group in comparison to the higher status group. Examples of collective strategies could include joining online social networks, support groups or autism rights organisations. Camouflaging, in its aims to minimise or mask features of autism, may be seen as attempts to dissociate from an autistic identity in order to and "pass" as neurotypical, thus appearing to represent an individualistic strategy to gain a positive social identity in response to a stigma.

Considering camouflaging through this theoretical framework presents new hypotheses around the precipitants and consequences of camouflaging. If camouflaging may be understood as an individualistic strategy in response to a stigmatised social identity, it implies that autism-related stigma motivates autistic people to camouflage. This hypothesis is supported by qualitative accounts of camouflaging that cite reducing stigma and avoiding rejection as motivators for camouflaging (Cage & Troxell-Whitman., 2019; Tierney et al.,

³ A person's sense of themselves based on their perceived group membership(s) (Tajfel & Turner, 1979).

2016). It is also supported by Botha and Frost's (2018) surveys with 142 autistic people that found physical concealment of autistic traits were positively associated with autism-related stigma and experiences of victimisation and discrimination. However, concealment of autism may not account for the full concept of camouflaging which includes attempts to compensate and assimilate (Hull et al., 2017). Consequently, in order to assess whether camouflaging is a response to the stigmatised social status of autism, the relationship between stigma and camouflaging requires quantitative investigation.

The proposed framework also directs hypotheses around the mechanisms through which camouflaging could relate to wellbeing. For example, if camouflaging does represent an individualistic strategy, one way it may relate to wellbeing is through preventing the use of collective strategies. By dissociating from one's group, individualistic strategies are thought to undermine connection to one's ingroup (prioritised by collective strategies), potentially eliciting guilt and shame and reducing access to ingroup support which may have buffered wellbeing (Branscombe et al., 2012). Hull et al. (2017) found that whilst autistic people did not describe disconnection from the autism community, they described feeling that they had betrayed the community by camouflaging and it undermining their relationships with others.

Accordingly, to assess whether camouflaging represents an individualistic strategy, its relationship to individualistic and collective strategies must be examined. If it is an individualistic strategy, one would expect that it positively

relates to individualistic strategy use and negatively or shows no relationship to collective strategy use.

Individualistic strategies are also theorised to reinforce the devalued status of the stigmatised group by implicitly confirming its unacceptable nature (Branscombe et al., 2012). In this way, camouflaging could impact on wellbeing by increasing one's sense of internalised stigma. This hypothesis is also partially supported by Botha and Frost's (2018) findings that physical concealment of autistic traits were positively associated with stigma, and internalised stigma was negatively associated with emotional wellbeing.

In order to assess whether camouflaging may be understood as an individualistic strategy in response to a stigmatised social identity this study will examine the hypotheses that camouflaging: 1) positively relates to experiences of autism related stigma, 2) positively relates to individualistic strategy use and negatively or shows no relationship to collective strategy use, 3) negatively relates to wellbeing and 4) mediates the relationship between stigma and wellbeing.

Methods

Participants

Three-hundred and two participants were included in the analyses, 184 participants identified as female, 61 male and 56 non-binary or used alternative gender terminology. Participants' age ranged from 18 to 65 years ($M = 34.36$, $SD = 10.87$), age at diagnosis (including self-diagnosis) ranged from 2 to 63 years ($M = 29.27$, $SD = 12.93$). Participant characteristics are presented in Table 1, indicating that the sample was mostly white and university educated.

An official autism diagnosis was not required to participate, to ensure the inclusion of those who have been unable to access a diagnosis (due to costs or perhaps as a result of camouflaging) but identify as part of the autistic community. This strategy has been used in other studies, such as Botha and Frost (2018). A total of 116 participants reported having a diagnosis of Asperger's Syndrome, 79 reported Autism Spectrum Condition or Disorder, 78 self-diagnosis, 23 Autism, two Pervasive Developmental Disorder Not Otherwise Specified, two "other" and one Atypical Autism.

Presence of diagnosable autistic traits was confirmed using Ritvo Autism and Asperger Diagnostic Scale (RAADS-14; Eriksson, Andersen & Bejerot, 2013) scores, a screening tool for autism. All participants scored above the cut-off score of 14 (range 14 to 42, $M = 33.71$, $SD = 6.34$).

Participants were recruited via online and offline communities through snowballing methods where recruitment posters (appendix 2) were posted on social media websites and emailed to relevant groups (Twitter, Facebook [e.g. the London Autism Group], Instagram, Reddit, autism community groups, charities and word-of-mouth) between November 2018 and January 2019. All participants gave informed consent before participating in the study and ethical approval was gained via the Research Ethics Committee at Royal Holloway, University of London (appendices 3 and 4).

Table 1.

Participant Characteristics Including Education, Ethnicity and Preferred Terminology.

		N	%
Education	None	10	3.3
	High school	36	11.9
	College	61	20.2
	Trade/Vocational	14	4.6
	Undergraduate degree	96	31.8
	Masters degree	55	18.2
	Doctorate	19	6.3
	Other	5	1.7
Ethnicity	White	276	91.4
	Mixed	11	3.6
	Asian	5	1.6
	Other	4	1.3
	Black	1	0.3
Preferred terminology	Autistic person	168	55.6
	Person with autism	36	11.9
	No preference	86	28.5
	Other	12	4

Materials and procedure

Participants completed an online survey using the Qualtrics online survey platform. After giving informed consent (appendix 5), participants completed the measures detailed in the order below. The survey was developed in consultation with an autistic person who completed a semi-structured interview relating to the relevance of the study to the autistic community, the readability and cultural sensitivity of the materials and estimated completion time. On completion of the survey, participants were thanked for their participation and a debriefing form (appendix 6) was presented which included support information and the researcher's contact details. Finally, participants were given the option to enter a prize draw as thanks for their time.

Language preference

Given the importance of language to one's sense of identity (Kenny et al., 2016), participants were first given the option to select their preferred terminology to customise the questionnaire (person with autism; autistic person; no preference; or other). Based on participant's selections, participants were either shown person first, identity first language in the subsequent measures, or a combination of both terms if 'other' or 'no preference' was selected.

Individualistic strategy use

Nario-Redmond et al.'s (2013) 13-item measure of individualistic strategy use was utilised. The original scale relates to disability identity, thus minor

revisions were made to adapt the scale to autistic identity (e.g. replacing the term 'disability' and 'disabled' with 'autism' and 'autistic'). Items related to denying or minimising the importance of autism (e.g. 'I don't think of myself as a [person with autism/autistic person]') and individual striving to overcome autism (e.g. 'I do not need to be "cured" of autism'). Participants rated each item using a 7-point Likert scale; from strongly disagree (1) to strongly agree (7). Scores could range between 13 and 91. Higher scores indicated greater use of individualistic-strategies. The scale had not been used with autistic populations previously. In the current sample, internal consistency was acceptable ($\alpha=.76$).

Collective strategy use

Nario-Redmond et al.'s (2013) 13-item measure of collective strategy use was utilised. As above, the original scale related to disability identity and as such minor revisions were made to adapt the scale to autistic identity. Items related to expression of community or community pride (e.g. 'Autism culture is alive and well'), valuing experience (e.g. 'Autism enriches my life') and support for social change (e.g. 'I am an autism rights activist'). Participants rated each item using the 7-point scale detailed above. Higher scores indicated greater use of collective strategies. The scale had not been used with autistic populations previously. Internal consistency was good ($\alpha=.89$).

The Stigma Consciousness Scale

The Stigma Consciousness Scale (Link & Whelan, 2014), is a 5-item scale that assesses awareness of one's stigmatised status and treatment. The

original scale relates to mental illness thus was adapted to autism (e.g. replacing 'mental illness' and 'mentally ill' with 'autism' and 'autistic'). Items included 'People knowing that I [am autistic/have autism] does not influence how they act towards me' and 'Most people do not judge someone on the basis of them [being autistic/having autism]'. Each item was rated on a 4-point Likert scale; from strongly agree (0) to strongly disagree (3). Scores could range between 0 and 15. Higher scores indicated greater awareness of stigmatisation. The scale had not been used with autistic populations previously. Internal consistency was questionable ($\alpha=.66$).

The Camouflaging Autistic Traits Questionnaire

The Camouflaging Autistic Traits Questionnaire (CAT-Q; Hull et al., 2019), is a 25-item measure of camouflaging. The measure utilises statements relating to monitoring, copying and practicing social behaviours, for example, "In my own social interactions, I use behaviours that I have learned from watching other people interacting". Each item was rated on a 7-point Likert scale from strongly disagree (1) to strongly agree (7). Scores could range between 25 and 175. Higher scores indicated greater camouflaging. The CAT-Q has been used with two large autistic populations and shown to have good to excellent internal consistency and acceptable test-retest reliability (Cage & Troxell-Whitman, 2019; Hull et al., 2019). In the current sample, internal consistency was excellent ($\alpha=.90$)

Warwick-Edinburgh Mental Wellbeing Scale

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Stewart-Brown & Janmohamed, 2008), is a 14-item measure of wellbeing. Items are positively framed and cover both feeling and functioning aspects of mental wellbeing. Example items include, 'I've been feeling relaxed' and 'I've been interested in new things'. Each item was rated on a 5-point Likert scale; from none of the time (1) to all of the time (5). Scores could range from 14 to 70. Higher scores indicated greater wellbeing. The WEMWBS has been used with multiple autistic populations and shown to have high reliability and correlate with other measures of distress (Arnold et al., 2019; Hull et al., 2019). Internal consistency was excellent ($\alpha=.91$)

Ritvo Autism and Asperger Diagnostic Scale

The RAADS-14 (Eriksson et al., 2013) is a 14-item self-report screening tool for autism in adult psychiatric populations. It assesses the presence of autism symptoms based on the diagnostic criteria for Autistic Spectrum Disorder and Asperger's Syndrome (DSM-IV-TR and ICD-10 equivalent). Items relate to experiences of social interactions, sensory stimulation and routine, for example, 'I focus on details rather than the overall idea' and 'I often don't know how to act in social situations'. Items were rated on a 4-point Likert scale; from never true (0), true only when I was younger than 16 (1), true only now (2) and true now and when I was young (3). Scores could range from 0 to 42. Higher scores indicated greater autistic traits. Eriksson et al. (2013) demonstrated sensitivity of .97 and specificity of .46 to .68 among a sample of autistic adults and psychiatric controls. RAADS-14 scores have been used to

confirm presence of autistic traits above diagnostic threshold (scores of 14 and above). Internal consistency was acceptable ($\alpha=.72$)

Demographic questions

Finally, participants were asked to report their age, age at diagnosis, official diagnosis (if applicable), gender, ethnicity and level of education.

Design

A cross-sectional, single group, correlational design was used. Required sample sizes were calculated for each analysis using G*Power version 3.1.9.3 on the basis of a multiple linear regression with predicted power of 0.8 and small effect size (0.15). Analyses for Hypothesis One and Three (5 predictors) each required 92 participants, Hypothesis Two (6 predictors) required 98 participants and Hypothesis Four (equivalent to 2 predictors) 68 participants.

Data analysis

Prior to the analyses, the dataset was cleaned to remove 65 participants with invalid responses, leaving 302 participants included in the analyses.

Participants who (a) did not finish the questionnaire ($n=43$), (b) had 33% or more missing data on at least one scale ($n=2$), (c) did not report above threshold autistic symptomatology according to RAADS-14 ($n=7$), (d) were under 18 or did not report their age or age at diagnosis which could indicate age >18yrs ($n=13$) were excluded from the data-set prior to analysis. For the remaining cases, missing data were imputed using the participant's average scores for the relevant scale ($n=31$). Statistical analyses were conducted in

SPSS version 22 and the PROCESS ad-on version 3.3. Two dummy variables were created for gender; 'female versus male' and 'female versus non-binary' (0 indicated female and 1 indicated male or non-binary).

Hypothesis One (that stigma will relate positively to camouflaging) was assessed using a multiple regression with camouflaging as the dependent variable, and stigma and demographic variables (age, age at diagnosis, gender and autistic traits) as independent variables. This analysis was to assess the relationship between stigma and camouflaging with the effects of demographic variables held constant. Assumptions of linearity, multicollinearity, independence, homoscedasticity, normality and influential outliers were met.

Hypothesis Two (that camouflaging will demonstrate a positive relationship with individualistic strategy use and negative or non-significant relationship with collective strategy use) was investigated using a three-stage hierarchical regression with camouflaging as the dependent variable. Demographic variables (as above) were entered at stage one, individualistic strategy use was entered at stage two and collective strategy use at stage three. This analysis enabled assessment of whether individualistic strategy use uniquely accounted for significant variance in camouflaging and whether the nature of the relationship to camouflaging differed to collective strategy use. All assumptions for the analysis were met.

Hypothesis Three (that camouflaging will relate to wellbeing) was investigated using a two-stage hierarchical regression with wellbeing as the dependent variable. Demographic variables (as above) were entered at stage one and camouflaging at stage two. This analysis enabled assessment of whether camouflaging uniquely accounted for significant variance in wellbeing. Assumptions were met, with the exception of extreme cases, where 7.3% of the standardised residuals were between -2 and 2. These cases were removed leaving 280 participants included in this analysis.

Hypothesis Four (that camouflaging will mediate the relationship between stigma and wellbeing) was assessed using a mediation analysis. Wellbeing was the dependent variable, stigma the independent variable and camouflaging the mediator. Assumptions of linearity, normality and independence were met.

Results

Means and standard deviations for each of the independent variables are presented in Table 2. Correlations between independent variables are presented in Table 3.

Table 2.

Means and standard deviations for independent variables.

	Mean	<i>SD</i>
Collective strategy	64.39	12.88
Individualistic strategy	45.32	10.62
Stigma	10.49	2.48
CATQ	127.51	21.00
WEMWBS	39.12	9.18

Table 3

Pearson Correlations (two-tailed) between independent and dependent variables.

	Age	Age at diagnosis	Education	Female vs Male	Female vs Non Binary	Collective Strategy	Individualistic Strategy	Stigma	CATQ	WEMWBS
Age at diagnosis	.87**									
Education	.21**	.20**								
Female vs Male	.10	.04	-.05							
Female vs Non-Binary	-.12*	-.11	-.04	-.24**						
Collective Strategy	-.03	.02	-.01	-.17**	.15**					
Individualistic Strategy	-.03	-.04	.08	-.01	-.15**	-.54**				
Stigma	-.03	.08	.09	.01	.20**	.16**	-.32**			
CATQ	-.01	.15*	.03	-.14*	-.01	.10	.11	.25**		
WEMWBS	.06	-.06	.23**	-.04	-.01	.19**	.03	-.22**	-.18**	
RAADS	-.01	.10	-.15**	-.01	-.05	.07	-.29**	.24**	.17**	-.29**

Note. ** $p < .01$, two-tailed. * $p < .05$, two-tailed.

Hypothesis One: stigma will relate positively to camouflaging

The multiple regression found that stigma, age, age at diagnosis and female gender contributed significantly to the regression model, $F(6, 296) = 8.06$, $p < .001$) and accounted for 14.1% of the variation in camouflaging (Table 4).

Stigma was a significant predictor of camouflaging, such that the model predicts that 1 unit increases in stigma scores are associated with 0.21 unit increase in camouflaging scores (Figure 1). Accordingly, the data provides support for Hypothesis One, that stigma will relate positively to camouflaging (i.e. camouflaging will increase with greater report of autism related stigma).

Table 4.

Regression model examining the relationship between stigma and camouflaging.

Predictor	β	t	p
Stigma	.21	3.66	<.001
Age	-.28	-2.97	.003
Age at diagnosis	.35	3.64	<.001
Female vs Male	-.15	-2.58	.010
Female vs Non-Binary	-.09	-1.58	.114
RAADS	.09	1.53	.127

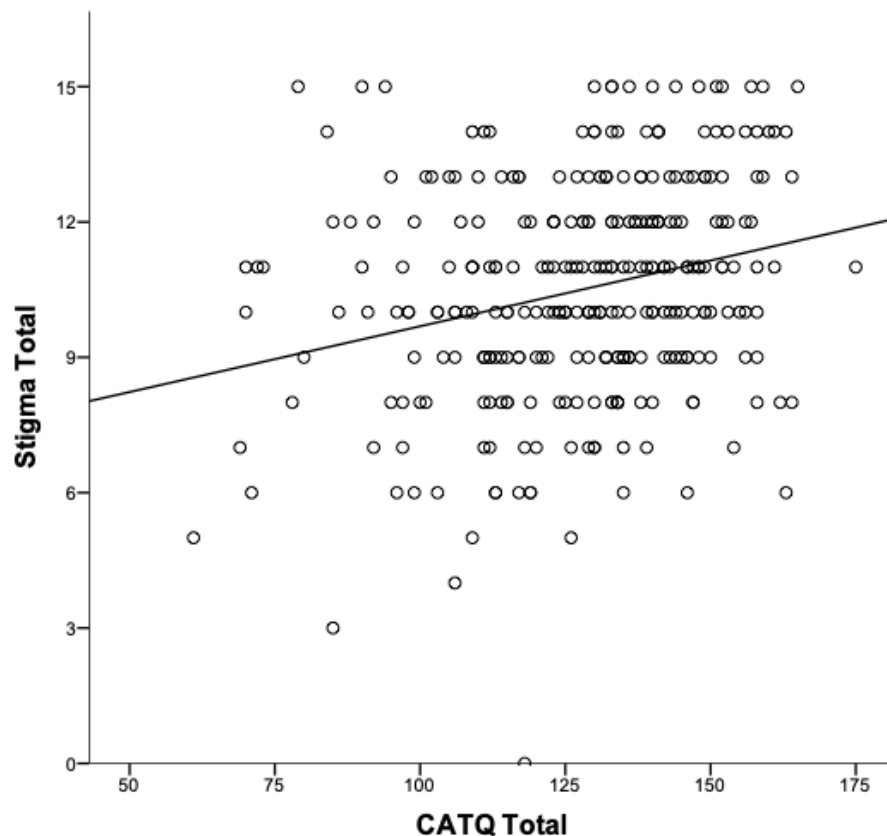


Figure 1. The relationship between stigma and camouflaging total scores.

Hypothesis Two: camouflaging will relate positively with individualistic strategy use and negatively, or show no relationship with collective strategy use

The hierarchical multiple regression found that at step one, age, age at diagnosis, female gender and autistic traits contributed significantly to the regression model, $F(5, 296) = 6.71, p < .001$) and accounted for 10.2% of the variation in camouflaging (Table 5). In the second step, including individualistic strategy use explained an additional 2.3% of variation in camouflaging, which was a significant change, $F(1, 295) = 7.88, p = .005$. Individualistic strategy use was a significant predictor of camouflaging (Figure

2). In the final step, adding collective strategy use explained a further 3.1% of the variation in camouflaging and this change in R^2 was also significant, $F(1, 294) = 10.72, p = .001$. In the final model, age, age at diagnosis and RAADS score remained significant predictors of camouflaging but female versus male gender was no longer a significant predictor. Individualistic strategy use remained a significant predictor of camouflaging, and collective strategy use was also a significant predictor (Figure 3). The model predicted that 1 unit increases in individualistic and collective strategy scores are associated with 0.28 and 0.22 unit increases in camouflaging scores respectively. The results provide partial support the hypothesis, i.e. that camouflaging demonstrates a positive relationship with individualistic strategy use. However, the results do not support the hypothesis that camouflaging will demonstrate a negative or non-significant relationship with collective strategy use.

Table 5.

Regression model examining the relationship between individualistic and collective strategy use and camouflaging.

Step	Variable	β	t	p
1	Age	-.33	-3.42	.001
	Age at diagnosis	.40	4.15	<.001
	Female vs Male	-.13	-2.26	.025
	Female vs Non-Binary	-.05	-0.82	.413
	RAADS	.13	2.31	.022
2	Age	-.32	-3.31	.001
	Age at diagnosis	.39	4.12	<.001
	Female vs Male	-.12	-2.16	.032
	Female vs Non-Binary	-.02	-0.39	.699
	RAADS	.18	3.04	.003
	Individualistic strategy	.16	2.81	.005
3	Age	-.29	-3.06	.002
	Age at diagnosis	.37	3.89	<.001
	Female vs Male	-.09	-1.54	.124
	Female vs Non-Binary	-.03	-0.50	.615
	RAADS	.20	3.47	.001
	Individualistic strategy	.28	4.18	<.001
	Collective strategy	.22	3.27	.001

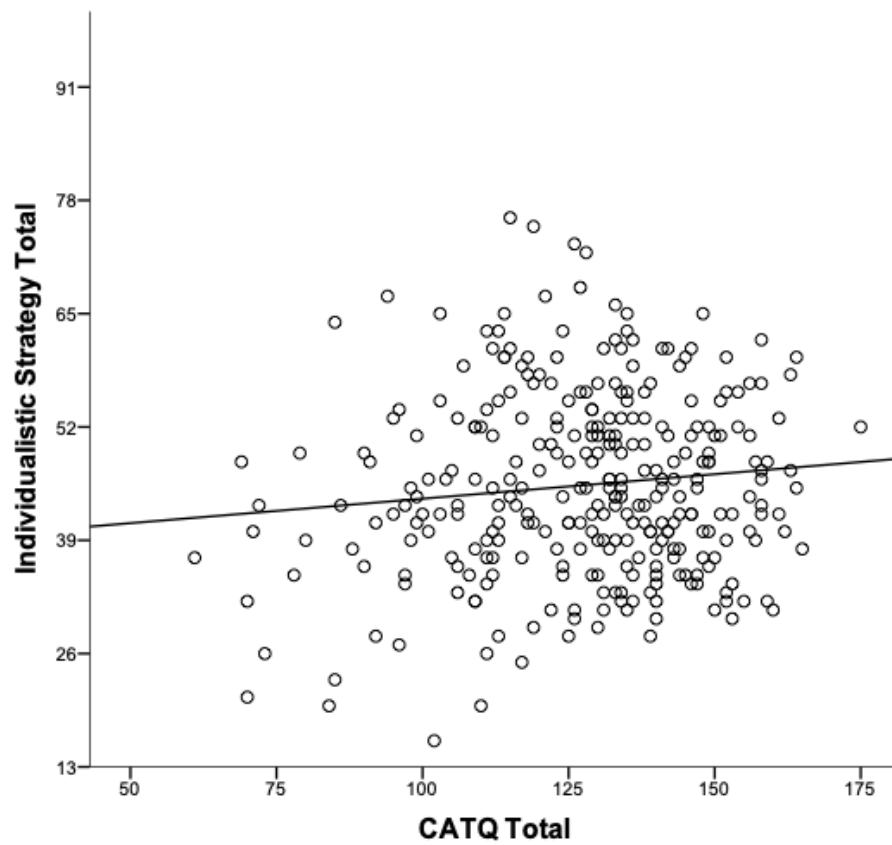


Figure 2. The relationship between individualistic strategy and camouflaging total scores.

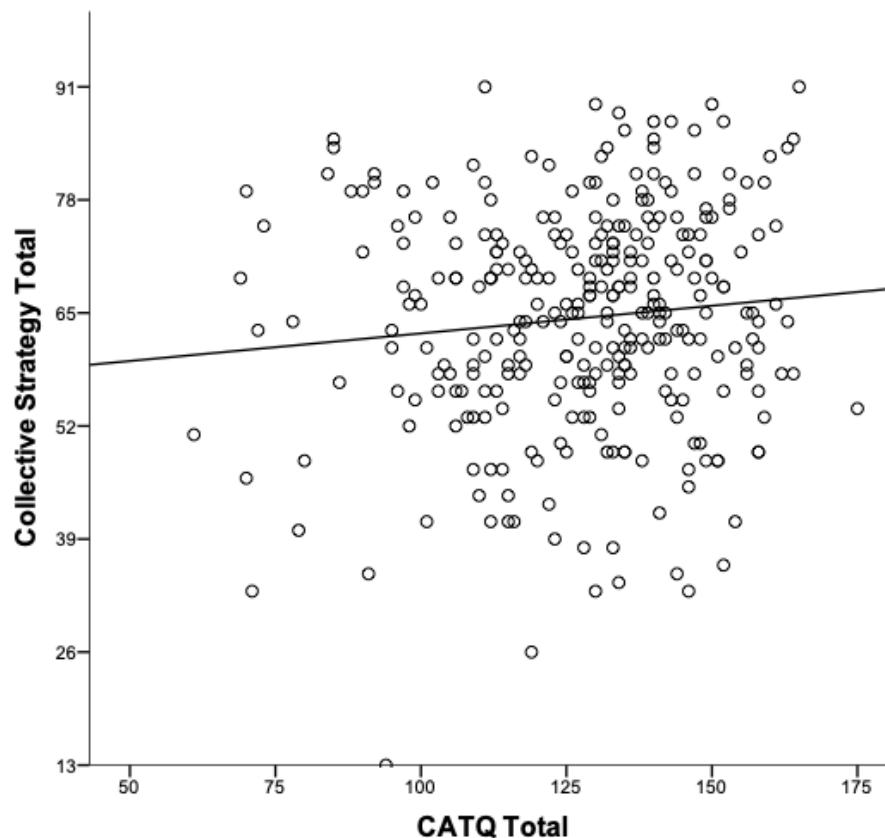


Figure 3. The relationship between collective strategy and camouflaging total scores.

Hypothesis Three: camouflaging will relate to wellbeing

The hierarchical multiple regression found that at step one, age, age at diagnosis and autistic traits, contributed significantly to the regression model, $F(5, 274) = 11.67, p < .001$) and accounted for 17.6% of the variation in wellbeing (Table 6). In the final model, including camouflaging explained an additional 1.5% of variation in wellbeing, which was a significant change, $F(1, 273) = 10.74, p = .024$. Camouflaging was a significant predictor of wellbeing (Figure 4), and the model predicts that 1 unit increases in camouflaging scores are associated with 0.13 unit decrease in wellbeing scores. The results support the hypothesis that camouflaging relates to wellbeing.

Table 6.

Regression model examining the relationship between camouflaging and wellbeing.

Step	Variable	β	t	p
1				
	Age	.32	3.26	.001
	Age at diagnosis	-.26	-2.68	.008
	Female vs Male	-.05	-0.96	.339
	Female vs Non-Binary	.04	0.63	.531
	RAADS	-.36	-6.39	<.001
2				
	Age	.27	2.79	.006
	Age at diagnosis	-.21	-2.13	.034
	Female vs Male	-.07	-1.26	.209
	Female vs Non-Binary	-.03	-0.54	.592
	RAADS	-.34	-6.06	<.001
	CATQ	-.13	-.2.28	.024

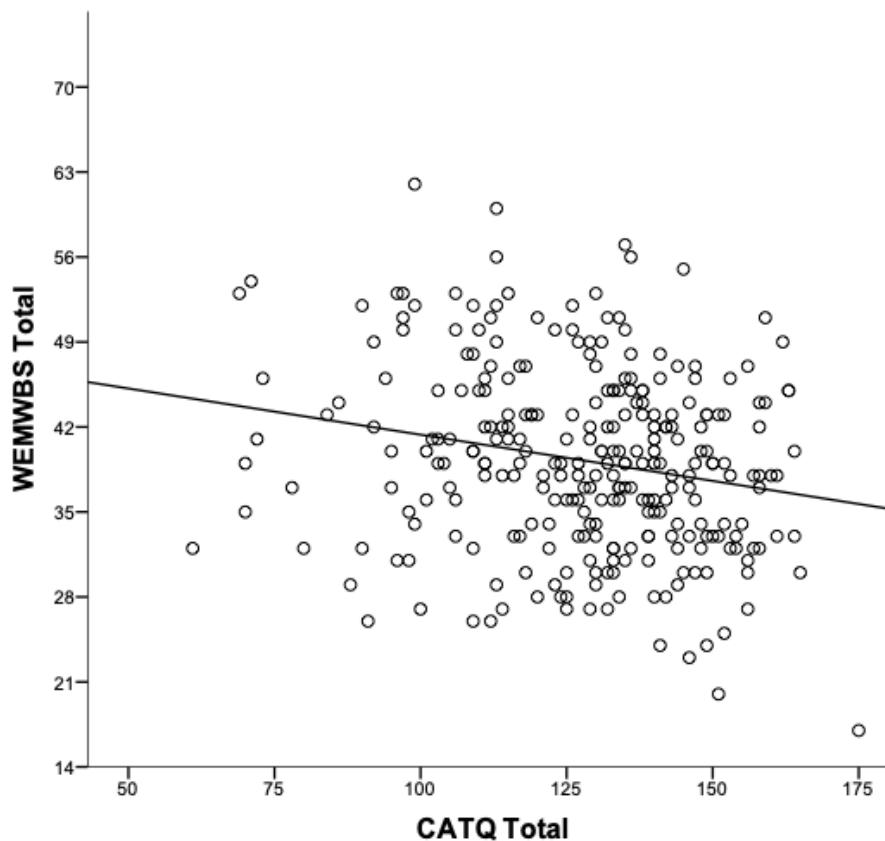


Figure 4. The relationship between camouflaging and wellbeing total scores.

Hypothesis Four: camouflaging will mediate the relationship between stigma and wellbeing

The mediation analysis found a significant direct effect of stigma on wellbeing, $b = -0.70$, $t(299) = -3.30$, $p = .001$ and a meaningful indirect effect through camouflaging $b = -0.12$, 95% CI $[-0.27, -0.001]$ (Figure 5). Accordingly, stigma was found to positively relate to camouflaging, and negatively relate to wellbeing, both directly and indirectly through camouflaging. Camouflaging related negatively to wellbeing. A Sobel test, which conducts formal tests of significance for the indirect effect was not performed. The Sobel test is considered to be low powered, present less accurate confidence intervals and

assume a normal distribution (that cannot be guaranteed in empirical studies such as this; Field, 2013; Hayes, 2018). Accordingly, 95% confidence intervals are presented. As the confidence intervals do not contain zero, there is likely to be a genuine indirect effect, supporting the hypothesis that camouflaging mediates the relationship between stigma and wellbeing.

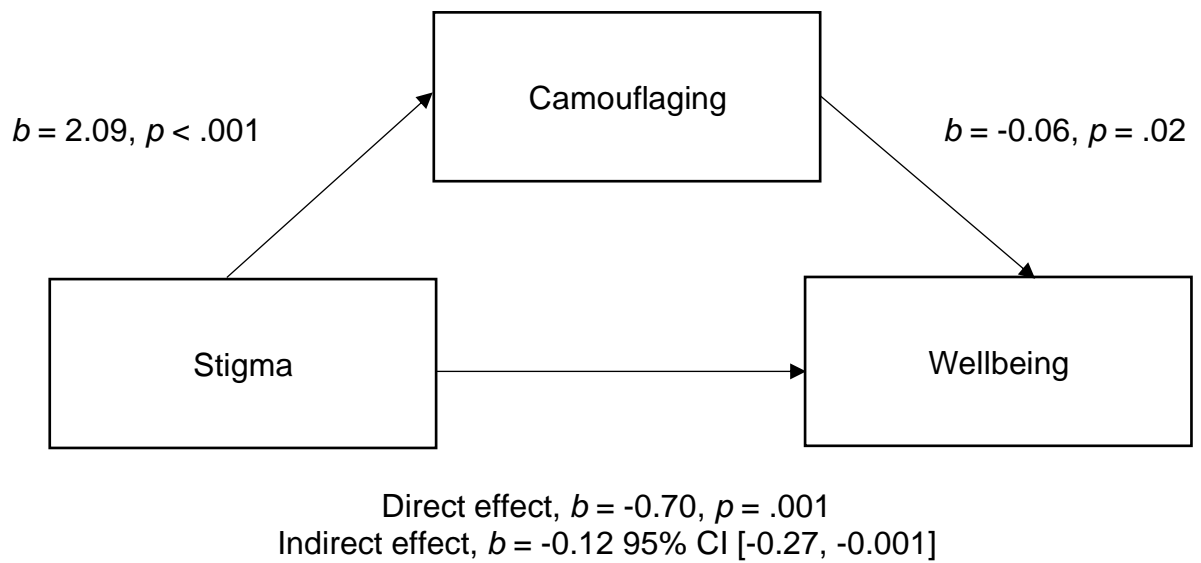


Figure 5. Mediation model examining the relationships between stigma, camouflaging and wellbeing.

Discussion

The present study examined the theory that camouflaging represents an individualistic strategy in response to the stigmatised social status of autism. Hypothesis One, that stigma will relate positively to camouflaging, was supported. Increases in autism stigma consciousness predicted greater self-reported camouflaging (alongside younger age, older age at diagnosis and female gender). Hypothesis Two, that camouflaging will show a positive relationship with individualistic strategy use and a negative or non-significant relationship with collective strategy use was partially supported. Increases in both self-reported individualistic and collective strategy use predicted greater camouflaging (alongside younger age, older age at diagnosis and greater autistic traits). Hypothesis Three, that camouflaging will relate to wellbeing was also supported, where greater camouflaging predicted decreases in self-reported wellbeing (alongside older age, younger age at diagnosis and fewer autistic traits). Finally, Hypothesis Four, that camouflaging will mediate the relationship between stigma and wellbeing was supported. Autism stigma was found to have a negative effect on wellbeing, which was mediated by camouflaging scores, suggesting that stigma influences wellbeing through its effect on camouflaging.

Hypothesis one: stigma will relate positively to camouflaging.

The positive relationship between autism-related stigma and camouflaging could indicate that camouflaging develops in response to autistic people's awareness of the stigmatised status of autism and their direct experiences of

stigma. From a SIT (Tajfel & Turner, 1979) perspective, the findings suggest camouflaging could be motivated by a desire to avoid experiences of stigma and obtain the advantages afforded to neurotypical people (i.e. social inclusion and employment). This interpretation fits autistic people's descriptions of their motivations for camouflaging, that include internalised stigma, a desire to fit in and gain acceptance (Bargiela et al., 2016; Cage & Troxell-Whitman, 2019; Hull et al., 2017). The findings also add to previous literature that found an aspect of camouflaging; physical concealment of autistic traits positively related to internalised autism stigma, victimisation and discrimination (Botha & Frost, 2018). The present findings indicate that a range of camouflaging strategies, such as compensation and assimilation (that are measured by the CAT-Q) may also be motivated by awareness and experiences of stigma.

However, due to the correlational, cross-sectional design of this study, causation and the direction of the relationship between stigma and camouflaging cannot be inferred. It could be argued that camouflaging raises one's awareness of the stigmatisation of autism, perhaps by being exposed to others' stigmatising views when one's autistic status is concealed and by noticing that one experiences greater discrimination when one is not camouflaging. This interpretation may be supported by Cage and Troxell-Whitman's (2019) finding that autistic people describe experiencing greater violence, intimidation, bullying and harassment when "out" as an autistic person compared to when camouflaging.

The present findings also add to the literature that acknowledges the stigmatisation of autism and the utility of understanding autistic people's experiences, such as camouflaging through a minority model (Beardon & Edmons, 2007; Botha & Frost, 2018; Cage & Troxell-Whitman, 2019; Cameron, 2014; Shtayermman, 2009). The social model of disability argues that society's notions of what is "normal", as opposed to the presence of a medical deficit, creates disability (Altman, 2001; Smart, 2006). This understanding has been applied to autism, where autism is considered part of neurodiversity (i.e. natural human variation) and central to people's social identities rather than a disorder (Bagatell, 2010; Botha & Frost, 2018; Brown, 2017; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). It is argued that social groups who are devalued on the basis of social norms (i.e. stigmatised) experience greater social stress, leading to greater physical and mental health problems (Schwartz & Meyer, 2010). The results of the present study may reinforce the applicability of this model to autistic people by demonstrating the link between experiences of stigmatisation and camouflaging. From this perspective, camouflaging may manifest in response to the stress of being 'othered' in social situations. This interpretation is supported by qualitative accounts of camouflaging that describe it as motivated by an expectation to be neurotypical in social situations (Cage & Troxell-Whitman, 2019).

Hypothesis two: camouflaging will relate positively with individualistic strategy use and negatively, or show no relationship with collective strategy use

Greater individualistic strategy use was found to predict increases in camouflaging. This finding lends further support to the hypothesis that camouflaging represents an individualistic strategy, indicating that camouflaging reflects attempts to dissociate from an autistic social identity and “pass” as neurotypical in order to gain upward social mobility. Qualitative accounts of camouflaging appear to bear striking similarities to descriptions of individualistic strategies (e.g. referring to camouflaging as “pretending to be normal” in order to progress socially, academically and within employment as a result), further endorsing this hypothesis (Cage & Troxell-Whitman, 2019; Hull et al., 2017).

However, the finding that camouflaging is predicted by both greater individualistic *and* greater collective strategy use may undermine the theory that camouflaging represents an individualistic strategy. Given that individualistic and collective strategies encompass contrasting strategies (i.e. rejecting versus embracing the stigmatised group) (Tajfel & Turner, 1979), if camouflaging represented an individualistic strategy one would expect it to only relate positively to individualistic strategy use. Indeed, correlations in the current study and in previous studies (Nario-Redmond et al., 2013) have shown individualistic and collective strategies to be significantly negatively correlated. The present findings suggest that whilst camouflaging bears several likenesses to an individualistic strategy (e.g. evidenced by its positive

relationship to an individualistic strategy and stigma, and negative relationship to wellbeing) it differs in its positive relationship to collective strategy use.

The finding that collective strategy use positively predicted camouflaging suggests that camouflaging may co-occur with embracing and advocating for the autistic community (Allen-Read, 2015; Nario-Redmond et al., 2013).

Nario-Redmond et al.'s. (2013) research with disabled adults found collective strategy use positively correlated with collective self-esteem. This finding would indicate that camouflaging could co-occur with a positive social identity as an autistic person (i.e. sense of worth and esteem gained through membership to the autistic community). This interpretation fits with autistic people's accounts of camouflaging, describing pride in relation to being autistic and part of the community, but still camouflaging - which was associated with a sense of betrayal to the community (Hull et al., 2017).

Together the findings reinforce Cage and Troxell-Whitman's (2019) findings that autistic people are forced to weigh up the significant personal and social costs of camouflaging against potential gains (e.g. protection against discrimination).

The relationship between collective strategy use and camouflaging may have implications for the relationship between stigma, camouflaging and wellbeing. As discussed, collective strategy use has been associated with greater self-esteem, and autistic identification, a potential consequence of collective strategy use has been associated with greater self-esteem and less symptoms of depression and anxiety (Cooper, Smith, & Russell, 2018; Nario-

Redmond et al., 2013). The present study also found positive correlations between collective strategy use and wellbeing. Together, the finding could suggest collective strategies have the potential to mediate the impact of stigma and camouflaging on wellbeing, perhaps by strengthening one's autistic identity and self-esteem.

Hypothesis three: camouflaging will relate to wellbeing.

The finding that camouflaging was a significant predictor of poorer wellbeing, controlling for the effect of demographic variables and autistic traits, replicates and strengthens Hull et al.'s (2019) findings of a negative correlation between camouflaging and wellbeing using the same measures. Interestingly, the results conflict with Botha and Frost's (2018) findings that physical concealment of autism did not correlate with emotional or psychological wellbeing but was a significant predictor of social wellbeing (the appraisal of one's circumstance and functioning in society, Keyes, 1998). The differences in results may be because concealment only represents one strategy involved in camouflaging. Camouflaging can involve masking (i.e. concealment); strategies used to hide autistic characteristics, compensation; strategies used to actively compensate for difficulties, and assimilation; strategies that reflect efforts to fit in with others (Hull et al., 2019). Thus, it may be that different camouflaging strategies relate differently to aspects of wellbeing.

In support of this hypothesis, Hull et al. (2019) found that assimilation was the only camouflaging strategy (i.e. not masking or compensation) to correlate significantly with wellbeing in autistic people. Furthermore, correlations Hull et

al. (2019) report between depression and anxiety and assimilation appeared to be of greater magnitude than those with masking or compensation (although the significance of these differences were not assessed). Together the findings could indicate that different camouflaging strategies interact differently with measures of wellbeing, and assimilation could constitute the most problematic camouflaging strategy (i.e. relates most negatively to wellbeing). Examining the individual relationships between camouflaging strategies (e.g. masking, compensation and assimilation) and different indicators of wellbeing (e.g. social and emotional wellbeing, depression) may further illuminate how and why camouflaging relates to wellbeing.

Hypothesis four: camouflaging will mediate the relationship between stigma and wellbeing

The negative relationship between stigma and wellbeing was found to be mediated by camouflaging, where greater camouflaging related to poorer wellbeing. From a SIT perspective, it could be argued that camouflaging, like individualistic strategies, negatively impacts on wellbeing by reinforcing or failing to challenge the stigmatised status of the group (Branscombe et al., 2012; Brune & Wilson, 2013). This interpretation may be supported by qualitative accounts of camouflaging that relate it to fulfilling expectations to appear neurotypical (Cage & Troxell-Whitman, 2019). Similarly, as described earlier, it may be that camouflaging heightens one's awareness of the stigmatisation of autism, reinforcing the devalued status of the group.

Equally, it could be argued that the significant efforts involved in camouflaging as a method of managing stigma, depletes one's psychological resources, leading to difficulties regulating one's emotions (Hatzenbuehler et al., 2013). For example, many autistic people describe camouflaging to require significant cognitive and emotional resources to process and mimic other's behaviours, and to manage uncomfortable physical and emotional responses (e.g. repressing self-stimulating behaviours and enduring long periods of anxiety) (Bargiela et al., 2016;; Hull et al., 2017). Therefore, it could be that camouflaging depletes one's available resources for managing stressors, meaning that such stressors have a greater impact on wellbeing (i.e. reducing wellbeing over time).

It could also be that the inner-conflict or dissonance generated by the use of collective and camouflaging strategies (that have potentially conflicting underlying values about being autistic and the autistic community) is detrimental to wellbeing. Similarly, it may be that concealing stigmatised parts of oneself prohibits autistic people's authenticity and authentic relationships with others, which is found to relate to wellbeing in the general population (Bottema-Beutel et al., 2018; Impett, Sorsoli, Schooler, Henson, & Tolman, 2008; Theran, 2010). Additionally, Hatzenbuehler et al. (2013) suggest that the "fear of being found out" when concealing one's stigmatised social identity could lead to social isolation which also may impact on wellbeing. Accordingly, whilst camouflaging is found to mediate the negative relationship between stigma and wellbeing, the mechanism through which this occurs requires further investigation.

Additional findings

Gender, late diagnosis and camouflaging

Older age at diagnosis and female gender were significant predictors of greater camouflaging across both models (hypothesis one and two) except when collective strategy use was added, where female gender was no longer significant. The findings could provide support for the theory that camouflaging relates to later diagnoses, particularly in women (Cage & Troxell-Whitman, 2019; Lai et al., 2017) as the results suggest those later diagnosed and female camouflage more. This finding fits with the accounts of autistic people and parents of autistic girls who consider camouflaging to have obstructed their access to diagnoses and support (Cook et al., 2018; Hull et al., 2017). Accordingly, the findings may reinforce the need for assessing clinicians to be aware of camouflaging (Zeldovich, 2017).

However, the finding that female gender no longer predicts camouflaging when collective strategy use is included in the model, could suggest the relation between female gender and camouflaging is accounted for by collective strategy use (i.e. women use collective strategies more, which is positively related to camouflaging). Correlations in the present study found female gender was positively associated with collective strategy use, further supporting this hypothesis.

Autistic traits, stigma and camouflaging

The present study found stigma and autistic traits were positively correlated. Previous research with autistic adolescents has found autistic traits were highly negatively associated with reports of stigma (Shtayermman, 2009). Other research with young adults (autistic and non-autistic) has found autistic behaviours positively related to stigmatisation, but diagnostic labels showed negative or non-significant relationships to stigmatisation (Brosnan & Mills, 2016; Butler & Gillis, 2011; Jones, Gallus, Viering, & Oseland, 2015). The disparity in the results could relate to the different research methods used across these studies, such as focusing on autistic versus non-autistic people's perspectives, adults and adolescents and a variety of measures of stigma and autistic traits. In research with autistic people, a key factor may be the extent to which measures of autistic traits rely on one's awareness of one's social difference and the responses one receives socially which could affect its relationship to stigma consciousness.

Interestingly, greater autistic traits significantly predicted increases in camouflaging in the second model (Hypothesis Two) but was not significant when stigma was included (Hypothesis One). Previously, Hull et al. (2019) found self-reported autistic traits significantly positively correlated with camouflaging and Botha and Frost (2018) found physical concealment of autism was positively associated with diagnostic status. The present findings could indicate that autistic traits or diagnostic status relate to camouflaging through their relationship to stigma (i.e. to the extent to which they increase one's experience of awareness of autism-related stigma).

Limitations

Although there was a relatively large sample, participants were predominantly white (91.4%), female (60.9%) and university educated (56.3%), who were likely to be verbally able in order to complete the materials. Therefore, the findings do not represent the experiences of a diverse range of autistic people, in particular those with high support needs, as is often a criticism of the autism literature (Pellicano, Dinsmore, & Charman, 2014). However, a strength of the current study is of the sampling of an adult autistic population, with a large proportion of female and non-binary identifying people, which have typically not been well represented in autism research (Cooper et al., 2018; Pellicano et al., 2014).

This study also included self-diagnosed autistic people and a screening tool was used to validate the presence of diagnosable autistic traits. This strategy is increasingly common in autism research (Botha & Frost, 2018). However, it could be argued that this reduces generalisability to a clinically diagnosed population as non-autistic people may have participated. However, it is widely acknowledged by the autistic community, clinicians and researchers that obtaining an autism diagnosis in adulthood can be difficult for a number of reasons, including the presence of camouflaging (Alley, 2019; Lewis, 2016; National Health Service, 2019). As self-diagnoses rise (Lewis, 2016), it is argued that research may be more generalisable to the autistic community as a whole to include the experiences of those unable to obtain diagnoses.

Whilst sampling via social media and autism community groups was the most feasible and effective method of recruiting autistic adults, it is important to consider how this may have affected the present findings. Recruitment sources of ranging ideologies were approached (i.e. autism rights, support and pro-cure groups) but few pro-cure organisations responded. Accordingly, the sample is likely to be largely recruited via affiliation to communities and individuals orientated towards autism rights and support. Therefore, the majority of participants were likely to be engaging in collective strategies to some extent. Subsequently, the results may be less generalisable to autistic people without such connections, where rates of individualistic and collective strategy use and the relationship to camouflaging and wellbeing may differ. Future research should attempt to recruit via non-autism focused and pro-cure communities to ensure the inclusion of a greater range autistic people.

The recruitment advert (appendix 2) may also have influenced the present findings by attracting particular subsets of participants and/or shaping the nature of participants' responses. For example, the description of the study "autistic people's experiences of stigma and camouflaging" may have appealed more greatly to individuals who endorse autism rights as opposed to pro-cure ideologies, (as the former group are likely to place more importance on the role of societal processes in framing autistic people's experiences and the latter may place more importance on 'reducing' autistic traits). Such individuals may be more attentive to or aware of their experiences of societal processes such as stigma, and place importance on autistic community, thus demonstrating potentially higher levels of stigma consciousness and/or

collective strategy use than other individuals. Similarly, some participants may have interpreted the description to indicate that the study was exploring a possible link between camouflaging and stigma. This may have led some participants to try to respond in ways to evidence this link (perhaps in particular to evidence a positive relationship, given the hypotheses outlined previously about participants' ideological positions). As a result the advert may have influenced the strength of the relationship demonstrated between camouflaging and stigma. Such potential consequences were considered during the development of the advert. The wording selected reflected a balance of multiple competing ethical priorities i.e. being transparent about the nature of the study without indicating the hypotheses or influencing the results.

Another consideration is the measures used. Measures of stigma consciousness, individualistic and collective strategy use were adapted to an autistic social identity and had not been validated in an autistic population. Whilst the strategy scales showed acceptable to good reliability, the stigma scale demonstrated questionable reliability. Such limitations could undermine the generalisability of the results. Accordingly, replication is needed using a range of validated measures.

Finally, the findings may be limited by the cross-sectional nature of the study. As has been noted, causation and the direction of the relationships observed cannot be inferred due to the correlational nature of the data. Longitudinal research is required to monitor the relationships between stigma

consciousness, camouflaging and wellbeing over time. Further, theorists note that social identity, strategy use and camouflaging is likely to fluctuate and be context dependent (Brune & Wilson, 2013; McDonald, 2017). Such variability is not captured in data collected at a single time point that does not enquire about contextual variations. As well as longitudinal research, future research should investigate how camouflaging and its relationship to social identity may vary across different contexts such as work, home, social groups (see Cage & Troxell-Whitman, 2019).

Implications

The current study implicates the need for the wider application of autism education and anti-stigma interventions for the general population. Multiple studies have shown that greater knowledge of autism and high-quality personal connections with autistic people are associated with lower stigma toward autism (Nevill & White, 2011; Gardiner & Larocci, 2014; Gillespie-Lynch et al., 2015; White, Hillier, Frye, & Makrez, 2016). Further, stigma reduction programs aimed at non-autistic adolescents and young adults are found to increase acceptance of autistic people, reduce stigma and increase knowledge of autism (Gillespie-Lynch et al., 2015; Obeid et al., 2015; Ranson & Byrne 2014; Staniland & Byrne 2013). The impact of these interventions on autistic people's wellbeing and camouflaging could be investigated in small communities such as schools, workplaces or social clubs where autistic people attend. Although this would only target one source of stigma (i.e. Gates (2019) highlights that the stigmatisation of autism occurs in many

settings and on many levels) this could provide insight into the potential causal relationship between stigma, camouflaging and wellbeing.

Recently, attention has been paid to the role interventions and the ideological orientations of organisations may have in stigmatising autism and necessitating camouflaging (Bottema-Beutel et al., 2018; Gates, 2019; Gillespie-Lynch et al., 2017). Gillespie-Lynch et al. (2017) found less interest in normalising autistic people was associated with lower stigma toward autism. The authors argue that interventions to normalise autism and cure-orientated organisations may therefore increase autism stigma. Similarly, Bottema-Beutel et al. (2018) suggest that social skills interventions for autistic people reinforce social arrangements that require autistic people to camouflage. Bottema-Beutel et al. (2018) recommend social skills interventions shift their focus from enforcing normative expectations to sharing information about neurotypical social interactions and encouraging autistic people to appraise these social arrangements rather than conform to them. The present findings would support these recommendations to reduce autism stigma. Accordingly, it is suggested that further research is needed into autistic people's experiences of interventions (throughout the lifespan) and their impact on their wellbeing and motivations to camouflage.

The results reinforce ICD-11 guidance (Zeldovich, 2017) for clinicians to be aware of camouflaging when assessing for autism, particularly in women. As autism diagnostic tools do not assess for the presence of camouflaging (Lord et al., 2015; Mandy et al., 2018), and effective camouflaging strategies may

be difficult for clinicians to observe, clinical assessments of autism may benefit from the inclusion of questions about camouflaging. To ensure valid and reliable assessment, standardised self-report tools such as the CAT-Q (Hull et al., 2019) may be trialled in clinical settings. However, as camouflaging may occur outside of autistic people's awareness, and autistic people can have difficulties with introspection (Hull et al., 2017; Sasson, Morrison, Pinkham, Faso, & Chmielewski, 2018) adult diagnostic process may benefit from an informant-report, similar to the parent CAT-Q (Hull et al., 2019) that could be used by a partner, friend or family member. Such changes may help to reduce late and misdiagnoses due to camouflaging.

However, it is important to note that late and misdiagnoses of autism may also be attributed to a number of clinical issues that also require attention, such as the complexities of diagnosis in adulthood (e.g. absence of parental-report, access to services and diagnostic over-shadowing) and clinician and referrers' awareness of the female phenotype (Lai & Baron-Cohen, 2015; Mandy et al., 2018). Consequently, to reduce late and misdiagnoses, it is important that clinicians are aware of and attend to the many barriers to adulthood autism diagnoses.

The present findings also indicate that clinicians should be aware of autistic people's experiences of stigma and camouflaging in relation to their mental health. Repeated experiences of autism-related stigma are increasingly recognised as a form of less-understood trauma (that bears similarities to racism) that may impact on individuals' health and functioning (Gates, 2019;

Sweeney, Filson, Kennedy, Collinson, & Gillard, 2018). This may be within or outside of an individual's awareness (Sweeney et al., 2018) and therapists should consider discussing with clients whether autism-related stigma is important to understanding their experiences and/or difficulties. Similarly, therapists should consider talking to autistic clients about camouflaging and its relationship to their wellbeing, whilst being mindful that for some autistic people talking about camouflaging may feel like being "outed" and evoke feelings of shame (Hull et al., 2017).

Conclusion

The present study examined the theory that camouflaging represents an individualistic strategy in response to the stigmatised social status of autism. Hypotheses were largely supported; camouflaging was positively predicted by autism-related stigma, individualistic and collective strategy use. Camouflaging was found to mediate the positive relationship between stigma and wellbeing. These findings indicate camouflaging relates to experiences of stigmatisation and lower wellbeing, and whilst it bears similarities to an individualistic strategy it differs in its positive relation to collective strategy use. The results add to an increasing body of literature that recognises the stigmatisation of autism and the utility of understanding autistic people's experiences, such as camouflaging through a minority model.

Chapter IV:

Integration, Impact and Dissemination Summary

Integration

The current project investigated factors relating to wellbeing in people with stigmatised social identities, specifically disabled and autistic people.

The project was theoretically grounded in SIT (Tajfel & Turner, 1979). The systematic review examined quantitative research investigating the relationship between identifying with one's stigmatised social identity (as a disabled person) and wellbeing. The empirical study examined the theory that camouflaging in autism represents a response to stigmatised social identity (being an autistic person) by investigating the relationship between camouflaging and autism-related stigma, individualistic and collective strategies and wellbeing.

The systematic review found that, when validated measures were used with disabled populations, disability identity related positively to wellbeing. The empirical study found that camouflaging was positively predicted by autism-related stigma, individualistic and collective strategies and negatively predicted wellbeing. These findings indicate that camouflaging relates to experiences of stigmatisation and lower wellbeing, similarly to an individualistic strategy but differs in its positive relation to collective strategy use. This section will consider to what extent the findings may be integrated

and the shared learnings that may be gained from the development of the two chapters.

The extent to which one identifies with one's social identity (such as being disabled or autistic) is theorised to relate to strategies used to manage stigmatisation, such as individualistic and collective strategies (Tajfel & Turner, 1979). Previous research has found that greater disability identity related to greater collective strategy use and lower individualistic strategy use (Nario-Redmond et al., 2013). As in the empirical study, camouflaging was positively predicted by both individualistic and collective strategy use, it would be interesting for future research to explore how camouflaging relates to autistic identity.

Given the negative relationship between camouflaging and wellbeing and positive relation between disability identity and wellbeing observed in the systematic review, one may expect camouflaging to relate negatively to autistic identity. However, it may be that camouflaging relates positively to autistic identity, through its association with collective strategy. Exploring how camouflaging relates to autistic identity, collective strategy use and wellbeing could provide further insight into how camouflaging relates to wellbeing and potential protective effects collective strategies may offer.

Similarly, the mechanism through which disability identity relates positively to wellbeing may be better understood by examining the role of collective strategy use. The empirical study added to existing findings that suggest

collective strategy use relates positively to wellbeing (Nario-Redmond et al., 2013). Given that disability identity may be defined by claiming disability status *and* connection to other disabled people (Dunn, 2014; Shakespear, 1996), it could be that collective strategies such as participating in ingroup activities is key to its connection to wellbeing. Future research should adopt longitudinal designs to examine the relationship between disability identity, collective strategies (e.g. within-group connection and activism) with wellbeing over time.

A difficulty with integrating the results of the systematic review and empirical study is that many autistic people, particularly from the neurodiversity movement⁴ do not identify with being disabled (i.e. consider autism to be a difference rather than a disability) (Jaarsma & Welin, 2012). Subsequently, the concept of disability identity (and related research) may not be relevant or applicable to autistic people. However, den Houting (2019), an autistic academic, argues that understanding autism as a difference rather than disability, is based on the social model of disability. This view considers the environment (that lacks adjustments for neurodiversity) to be disabling rather than autism in itself to be inherently disabling (den Houting, 2019). Consequently, the concept of disability identity (and related research), which is based on the social model of disability (i.e. claiming disabled status, connection to disabled people, viewing disability as non-devaluing) may be

⁴ Neurodiversity refers to variations in the human brain regarding sociability, cognitive functioning and mood (Kapp et al., 2013). The neurodiversity movement views 'conditions' such as autism as natural neurological differences as opposed to disorders and celebrates the diverse skills and ways of experiencing the world neurodiverse people have (den Houting, 2019).

argued to have considerable relevance to autistic identity (i.e. claiming autistic status, connection to autistic people, viewing autism positively; Cooper et al., 2018).

Challenges

Across the papers reviewed in the systematic review, there was a striking lack of adjustments to facilitate the participation of people with learning disabilities or impairments (e.g. visual impairment, communication needs, attentional difficulties etc). Given that the target population were disabled people who are most likely to have differences or impairments in abilities, one might expect there to have been greater attempts to make participation accessible (e.g. different formats for materials or responses, support for completion of materials and the use of assistive technology). As such, the generalisability of the conclusions drawn from these studies to disabled people with a full range of intellectual abilities and impairments is questionable.

Unfortunately, the empirical study is subject to the same limitations in terms of a lack of modifications made to the recruitment strategy. Consequently, the results are unlikely to reflect the experiences of autistic people with a full range of abilities and support needs. This limitation is particularly disappointing as to the authors knowledge, there has been no research into whether autistic people with learning disabilities experience of camouflaging. This lack of research on camouflaging may reflect a wider issue within autism research that despite estimates of between 50 and 70 percent of the autistic population having learning disabilities, the majority of autism research is

thought to have focused on those within the average to above average range of intelligence (den Houting, 2019; Hurley & Levitas, 2007; Matson & Shoemaker, 2009). Further, people with learning disabilities have also typically been excluded from the co-development of research, leading to a 'double exclusion' (O'Brien, McConkey, & García-Iriarte, 2014). Consequently, the experiences and priorities of autistic people with learning disabilities appear to be significantly overlooked and underrepresented in the literature. Future autism research, including projects focused on camouflaging should seek to include autistic people with a range of abilities and impairments during research development and participation.

Rios, Magasi, Novak, and Harniss (2016) provide clear guidance in relation to developing accessible research designs that include modifications for people with a range of disabilities and needs. These include modifying the presentation of materials during recruitment and participation (e.g. use of plain English, adjusting font, size and colour of text, offering audio or supported reading), adjusting response formats (e.g. audio or video) and increasing access to research facilities (e.g. ensure buildings are wheelchair accessible and near public transport). Future research concerning autistic and disabled people should be informed by such principles to ensure research reflects the experiences and views of people of a range of abilities.

On reflection, the systematic review would also have benefited from involvement of disabled people during the research process. The empirical study profited greatly from an autistic person providing consultation during the

design of the project, which led to the removal of potentially offensive language and adaptations to aid autistic people's completion of the materials (e.g. providing indication of upcoming questions and recommendations about completion time). Further, the British Psychological Society (2017) and NHS Improvement (2018) recommend researchers include experts by experience throughout the research process to ensure research 1) addresses a question valuable to the relevant community; 2) uses terminology that reflects community preferences; 3) uses suitable methodologies; and 4) includes interpretations from experts by experience not just experts by profession. Accordingly, the process of completing the empirical paper and reflection on the two projects has highlighted the importance of including experts by experience in future systematic reviews as well as empirical studies.

Impact

Systematic review

The results of the systematic review have important implications for a variety of individuals, not just disabled people, who are directly involved in the process of disability identity development. Given that identity development is fundamentally a social process, and identities are formed through a variety of processes (i.e. mirroring, modelling, and recognition of similar others) (Forber-Pratt, Lyew, Mueller, & Samples, 2017), the results are of significance to those involved in the lives of disabled people, who play a role in shaping disability identity development and subsequently wellbeing.

Forber-Pratt et al. (2017) highlight that disabled people may be developing identities around disabilities or impairments that their families, immediate circles and communities do not share (particularly when disability is acquired). Consequently, a major source for processing one's disability identity, may come from interactions with rehabilitation professionals, educators, and caregivers, who are often non-disabled. Forber-Pratt et al. (2017) suggest that these individuals have a key role in introducing disabled people to the wider disabled community.

The role of professionals, carers and educators may include practical help, such as directing disabled people to social, support and activism groups, charities and online forums for disabled people. Dunn and Burcaw (2013) also recommend practitioners encourage disabled people to read the narratives of

other disabled people to build connection to the disabled community and increase exposure to non-devaluing depictions of disability. They also recommend encouraging disabled people to write their own disability narrative, as this could aid the development of coping strategies and positive identity development (Dunn & Burcaw, 2013; Pennebaker, 1997; 2004; Wilson, 2011).

Forber-Pratt, Mueller, and Andrews (2019) highlight that to facilitate positive identity development, practitioners must also shift their understanding of their role within services. Forber-Pratt et al. (2019) argues that the orientation of practitioners toward disability and disability-identity may influence clients' relationship to disability and disability identity. As outlined earlier, professionals may be disabled people's first or most significant resource for processing disability identity and hold inherent power as *service providers* rather than *service users* (Forber-Pratt et al., 2017; 2019). Accordingly, Forber-Pratt et al. (2019) suggests practitioners must move away from the view that they are experts who must "fix" disabilities to allies to the disabled community who exchange knowledge and ideas. The former is considered to reinforce the medical model of disability which sees disability as a deficit that requires 'normalising', emphasising devaluing notions of disability that are at odds with positive disability identity development (Nario-Redmond et al., 2013). The latter places value in disability experience and the disabled community, constructing disabled people as worthy, able and equal peers, consistent with positive disability identity (Nario-Redmond et al., 2013).

The results also point to the importance of accessible spaces for disabled communities to develop and maintain connection and activism. Qualitative research with disabled people indicates that interaction with the disabled community is key to identity development (Goodwin & Staples, 2005; Gustafson, Elliott, Thurmeier, & Kuttai, 2009). This implication is of particular relevance to policy makers, local councils and charities who play a role in funding, organising and ensuring accessibility of events and spaces.

Similarly, the results may reinforce the importance of online communities for disabled people. Previously, research has questioned the value of online communications for building and sustaining social relationships compared to face-to-face communications (Cummings, Butler, & Kraut, 2002; Ducheneaut, Yee, Nickell, & Moore, 2006). However, some disabled people may have difficulty accessing communities in 'real life' and online communities may constitute an accessible resource for connection to other disabled people. Research indicates that greater participation in online disability support groups is related to greater disability identification and sense of disability community (Cummings, Sproull, & Kiesler, 2002; Obst & Stafurik, 2010). In addition, social media is increasingly utilised as a platform to challenge dominant narratives around disability and participate in disability activism (Trevisan, 2017; Pearson & Trevisan, 2015). Further, even when disability is not a feature of online communications, disabled people report developing connection to disabled peers through an implicit shared understanding of social experiences and contexts (Söderström, 2009). Accordingly, online communication with disabled peers appear to represent a significant tool for

developing disability identity, through connection to others and development of non-devaluing values (Wright, 1960; 1983). The present findings indicate such communications may be beneficial for wellbeing, perhaps challenging the view these communications are “lesser”.

The findings could also have implications for educational settings. Given the importance of interaction with the disabled community to identity development, the findings could indicate the significance of opportunities for disability community within mainstream schools for wellbeing. Research with hard of hearing children indicated that special hard of hearing classes in mainstream schools enabled the development of connection to other hard of hearing children, which was related to greater disability identity (Israelite, Ower, & Goldstein, 2002). However, as the review was only with adults, more quantitative research is needed with children to explore the relationship between disability identity and wellbeing, before such implications can be considered further.

Empirical study

The results of the empirical study also have important implications for a variety of individuals and are not limited to autistic people. By demonstrating the relationship between autism-related stigma, camouflaging and wellbeing, the results may contribute to the re-framing of camouflaging from an ‘individual problem’ to a ‘societal problem’ (Mills, 1959). That is, instead of camouflaging being considered a response to difficulties residing in an individual (i.e. attempts to compensate for autistic traits) it may be understood

as a response to social injustice (i.e. strategies to manage the stigmatisation of autistic traits) (Mills, 1959). Understanding camouflaging as a 'societal problem' moves away from the notion that camouflaging and the poorer wellbeing of autistic people is the responsibility of autistic people to resolve (i.e. individual intervention to reduce autistic traits or camouflaging) or calls to cure autism. Furthermore, it indicates the need for intervention to target societal injustice, placing the responsibility on society as a whole, including policy makers, educators and researchers to reduce autism-related stigma.

As highlighted in the empirical study, media, legislation, research and even autism charities are found to stigmatise or promote the stigmatisation of autism (Nicolaidis, 2012; Gillespie et al., 2017; Holton et al., 2014). Such organisations have a critical role in shaping public opinion and knowledge, and thus have a responsibility to provide fair, balanced, informative and non-discriminatory content (Holton et al., 2014). Autistic people and academics recommend that organisations avoid presenting sensationalised or polarised depictions of autistic people (Holton et al., 2014) and move from advocating for a cure of autism to increased acceptance, accommodations, and support for autistic people to reduce stigmatisation (den Houting, 2019; Gillespie et al., 2017; Harmon, 2010; Nicolaidis, 2012). Further, Holton et al. (2014) encourage organisations to connect with autistic communities to learn about autism and how the community would like to be represented.

Adults and children in the general population are also found to hold stigmatising attitudes towards autistic people (Brosnan & Mills, 2009;

Gillespie-Lynch et al., 2015; Sasson et al., 2017; Shcherbakov, 2016). As has been highlighted in the empirical study, greater knowledge of autism and quality connections with autistic people are associated with lower autism-related stigma (Nevill & White, 2011; Gardiner & Larocci, 2014; Gillespie-Lynch et al., 2015; White et al., 2016). Accordingly, individual members of society, educators and parents may reduce their own and others' stigmatising attitudes by seeking and sharing greater knowledge of autism and connection with autistic people.

The present research also reinforces the importance of attending to autistic people's preferences around the use of language (e.g. person-first: person with autism and identity-first: autistic person) to describe members of the autistic community. Following, Kenny et al.'s (2016) research that indicated whilst the majority of autistic people preferred identity-first language, there was no consensus amongst the autistic community, the empirical study enabled participants to select their preferred language to be used throughout the survey. Seventy-one percent of participants selected a preference for either identity-first (55.6%), person-first (11.9%) or another phrasing (4%) (i.e. as opposed to selecting 'no preference'), reinforcing the suggestion that the use language is important to autistic people, and that the majority prefer identity-first language (Kenny et al., 2016). The findings may have implications for non-autistic people communicating with autistic people in professional and personal capacities. Dunn and Andrews (2010) suggest respecting a person's language preferences around their identity promotes human dignity. Accordingly, asking autistic people about their preferred

language and adapting accordingly appears an easy and important way to demonstrate respect to autistic people. When communicating with a number of autistic people simultaneously (e.g. through the media) the present findings and previous literature (Kenny et al., 2016) indicate using identity-first language is likely to be the most appropriate selection.

The empirical study has emphasised the need for clinicians to be aware of camouflaging during assessment for autism (Zeldovich, 2017) and considered how the assessment process may benefit from standardised self and informant-report measures of camouflaging such as the CAT-Q (Hull et al., 2019). In addition, it is argued that referring clinicians have a significant role in obstructing or enabling assessments to take place (e.g. psychologists, psychiatrists, therapists, general practitioners) (Shah, 2001). Accordingly, it is recommended that clinical training on autism and professional development sessions include information on camouflaging.

Similarly, it has been suggested that knowledge of camouflaging is not just relevant to the assessment process and may be important to psychological therapy. Given the link between stigma, camouflaging and poorer wellbeing, it was recommended that therapists consider exploring the personal relationship between these factors for clients. Previous research has also suggested that therapeutic spaces offer autistic people the opportunity to “take off the mask” (i.e. not camouflage) and communicate their authentic selves (Cage & Troxell-Whitman, 2019). The present findings support such invitations, but caution that for some autistic people, not camouflaging may

relate to experiences of discrimination (see Cage & Troxell-Whitman, 2019) and thus require time to build trust that a therapist will not repeat such experiences. Accordingly, it is suggested that therapists negotiate with clients what may enable reducing camouflaging in sessions, if this is important to the client.

Dissemination

Academic

In order to disseminate the findings within the academic community, both the systematic review and the empirical article will be submitted for publication in scientific journals. For the systematic review, two relevant journals have been identified (i.e. *Disability and Rehabilitation* and *Clinical Rehabilitation*) to potentially target. Both publish research from the field of disability and rehabilitation including medical, practice and policy focused research, systematic reviews and have published articles reviewed in the project. They have impact factors of 1.77 and 1.80, which are indicative of relatively wide readerships. Accordingly, these journals appear suitable options to target in the first instance that could include a wide academic readership.

For the empirical study, the *Journal of Autism and Developmental Disorders* will be targeted initially. It aims to promote the wellbeing of autistic people by publishing articles on mental health, society, culture and policy and has an impact value of 3.47. Previous camouflaging research that has been key to the development of this paper (Cage et al., 2017; Cage & Troxell-Whitman, 2019; Hull et al., 2017; 2019) was published in this journal. Consequently, it is considered to be an appropriate journal to target that is likely to have a wide academic readership.

Depending on the time scale and conditions for journal publication, both the systematic review and empirical study will also be submitted for poster

presentations at academic conferences. Presenting the findings at conferences will hopefully increase the size and diversity of the academic readership and create opportunities to network with professionals who may wish to develop research in these areas. For the systematic review, *the World Disability & Rehabilitation Conference* (held in November 2019) has been identified. It focuses on the rights, research and challenges within the field of Disability & Rehabilitation. It is an annual interdisciplinary event for researchers, practitioners, policy makers, educators, industry experts, health and disability advocates. Accordingly, it offers an excellent opportunity to disseminate the results to a range of stake holders beyond academia. In particular, to those who may be able to consider the information in policy and planning decisions.

For the empirical study, *The International Conference on Stigma* (held in November 2019) will be targeted. It is an annual event that aims to connect research, practice and community around stigma. Attendees include individuals with stigmatised conditions or status, community and faith organisations, health care providers and researchers. Topics previously included were the impact of stigma on wellbeing, health outcomes for people affected by HIV, research methods and increasing collaboration with experts by experience. Accordingly, the empirical study appears a suitable submission. It is hoped that targeting the different academic field of stigma, as opposed to autism research, may widen the academic readership and increase the likelihood of the findings impacting on wider areas of research.

Community

In order to reach a range of audiences beyond academia, short summaries of the projects will be written in plain English with visual aids (e.g. relevant images and diagrams to aid understanding and increase engagement) and available in multiple formats (e.g. adjustable font size and audio versions) following journal publication. These will be distributed (along with a link to the publication) amongst relevant communities via email and social media. It is hoped that this will increase awareness of the results and readership of the full papers amongst a wider community of affected individuals, families, practitioners, organisations and policy makers.

For the systematic review, disability charities, (e.g. Scope, The Disabilities Trust and Mencap) relevant academics contacted during the project (e.g. Dr Nario-Redmond, Dr Marjorie Olney and Dr Rhoda Olkin) and social media ‘influencers’ will be approached. For the empirical study, the original recruitment sources (e.g. Twitter, Facebook, Reddit, Instagram, NAS groups and various additional communities), social media groups and ‘influencers’ (e.g. autistic people and autism parent groups) and autism charities will also be approached.

Clinical

In order to reach clinical psychologists working with, or likely to work with autistic people, a short presentation, summarising the empirical study will be developed. This presentation will focus on the clinical implications of the research. Following the ICD-11 guidance (Zeldovich, 2017) for clinicians to be

aware of camouflaging and coping strategies, this will also include relevant summaries of previous research that may help clinicians to identify camouflaging and different presentations of autism (i.e. autism in verbally able women who may not have a clinical diagnosis). It is hoped that this may support clinicians' effective assessment of autism in people who camouflage and identify individuals in need of mental health support.

This presentation will initially be presented to psychologists working at East London NHS Foundation Trust during a monthly professional development meeting and during a team meeting at the Adult Autism Service. Professional contacts from autism clinical services and autism research will also be approached to conduct further presentations.

References

- Allely, C. S. (2019). Understanding and recognising the female phenotype of autism spectrum disorder and the “camouflage” hypothesis: A systematic PRISMA review. *Advances in Autism*, 5(1), 14-37.
- American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders (Fifth edition)*. Arlington, VA: American Psychiatric Publishing.
- Andresen, E. M., Malmgren, J. A., Carter, W. B., & Patrick, D. L. (1994). Screening for depression in well older adults: Evaluation of a short form of the CES-D. *American Journal of Preventive Medicine*, 10(2), 77-84.
- Attawong, T., & Kovindha, A. (2005). The influencing factors of acceptance of disability in spinal cord injured patients. *Nepal Journal of Neuroscience*, 2(1), 67-70.
- Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos*, 38(1), 33-55.
- Barga, N. K. (1996). Students with learning disabilities in education: Managing a disability. *Journal of Learning Disabilities*, 29(4), 413-421.
- Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, 46(10), 3281-3294.

- Bat-Chava, Y. (1994). Group identification and self- esteem of deaf adults. *Personality and Social Psychology Bulletin*, 20(5), 494-502.
doi:10.1177/0146167294205006
- Beardon, L., & Edmonds, G. (2007). ASPECT consultancy report: A national report on the needs of adults with asperger syndrome. *Sheffield: The Autism Centre, Sheffield Hallam University*,
- Bogart, K. R. (2014). The role of disability self-concept in adaptation to congenital or acquired disability. *Rehabilitation Psychology*, 59(1), 107.
- Bogart, K. R. (2015). Disability identity predicts lower anxiety and depression in multiple sclerosis. *Rehabilitation Psychology*, 60(1), 105-109.
doi:10.1037/rep0000029
- Boland, A., Cherry, G., & Dickson, R. (2017). *Doing a systematic review: A student's guide* Sage.
- Boone, S. E., Roessler, R. T., & Cooper, P. G. (1978). Hope and manifest anxiety: Motivational dynamics of acceptance of disability. *Journal of Counseling Psychology*, 25(6), 551-556. doi:10.1037/0022-0167.25.6.551
- Botha, M., & Frost, D. M. (2018). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health*, , 2156869318804297.
- Bottema-Beutel, K., Park, H., & Kim, S. Y. (2018). Commentary on social skills training curricula for individuals with ASD: Social interaction,

authenticity, and stigma. *Journal of Autism and Developmental Disorders*, 48(3), 953-964.

Bowen, F., & Blackmon, K. (2003). Spirals of silence: The dynamic effects of diversity on organizational voice. *Journal of Management Studies*, 40(6), 1393-1417.

Boynton, L. D. S., & Chang, B. (1994). Effective coping with stroke disability in a community setting: The development of a causal model. *The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses*, 26(4), 193-203.

British Psychological Society. (2017). *Practice Guidelines, Third edition*.

Retrieved from

[https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Practice%20Guidelines%20\(Third%20Edition\).pdf](https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Practice%20Guidelines%20(Third%20Edition).pdf)

Brosnan, M., & Mills, E. (2016). The effect of diagnostic labels on the affective responses of college students towards peers with 'Asperger's syndrome' and 'Autism spectrum disorder'. *Autism*, 20(4), 388-394.

Brown, A. W., Mehta, T. S., & Allison, D. B. (2017). Publication bias in science: What is it, why is it problematic, and how can it be addressed? *The Oxford Handbook of the Science of Science Communication*, , 93-101.

- Brown, R. L. (2017). Understanding the influence of stigma and discrimination for the functional limitation severity–psychological distress relationship: A stress and coping perspective. *Social Science Research*, 62, 150.
- Brune, J. A., & Wilson, D. J. (2013). *Disability and passing: Blurring the lines of identity* Temple University Press.
- Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(12), 3063-3071.
- Burns, R. (2016) Psychosocial Well-being. In N. Pachana (Eds) *Encyclopedia of Geropsychology*. Springer, Singapore
- Butler, R. C., & Gillis, J. M. (2011). The impact of labels and behaviors on the stigmatization of adults with asperger's disorder. *Journal of Autism and Developmental Disorders*, 41(6), 741-749.
- Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, 48(2), 473–484.
- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders*, 1-13.
- Centre for Reviews and Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. York.

- Cameron, A. (2014). No title. *Stigma, Social Comparison and Self-Esteem in Transition Age Adolescent Individuals with Autistic Spectrum Disorders and Individuals with Borderline Intellectual Disability*,
- Chalk, H. M. (2016). Disability self- categorization in emerging adults: Relationship with self- esteem, perceived esteem, mindfulness, and markers of adulthood. *Emerging Adulthood*, 4(3), 200-206.
doi:10.1177/2167696815584540
- Cook, A., Ogden, J., & Winstone, N. (2018). Friendship motivations, challenges and the role of masking for girls with autism in contrasting school settings. *European Journal of Special Needs Education*, 33(3), 302-315.
- Crocker, J., & Major, B. (1989). Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review*, 96(4), 608.
- Cummings, J. N., Butler, B., & Kraut, R. (2002). The quality of online social relationships. *Communications of the ACM*, 45(7), 103-108.
- Cummings, J. N., Sproull, L., & Kiesler, S. B. (2002). Beyond hearing: Where the real-world and online support meet. *Group Dynamics: Theory, Research, and Practice*, 6(1), 78.
- den Houting, J. (2019). Neurodiversity: An Insider's Perspective [Editorial]. *Autism*, 23(2) 271–273.
- DeLoach, C., & Greer, B. G. (1981). *Adjustment to severe physical disability: A metamorphosis* McGraw-Hill Companies.

- Diener, E. D., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment*, 49(1), 71-75.
- Dijkers, M. (1997). Quality of life after spinal cord injury: A meta analysis of the effects of disablement components. *Spinal Cord*, 35(12), 829.
- Ditchman, N., Sung, C., Easton, A. B., Johnson, K. S., & Batchos, E. (2017). Symptom severity and life satisfaction in brain injury: The mediating role of disability acceptance and social self-efficacy. *NeuroRehabilitation*, 40(4), 531-543.
- Ducheneaut, N., Yee, N., Nickell, E., & Moore, R. J. (2006). Alone together?: Exploring the social dynamics of massively multiplayer online games. Paper presented at the *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 407-416.
- Dunn, D. (2014). *The social psychology of disability* Oxford University Press.
- Dunn, D. S. (2010). *The social psychology of disability*.
- Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255.
- Dunn, D. S., & Burcaw, S. (2013). Disability identity: Exploring narrative accounts of disability. *Rehabilitation Psychology*, 58(2), 148.
- Elfström, M. L., Kreuter, M., Rydén, A., Persson, L., & Sullivan, M. (2002). Effects of coping on psychological outcome when controlling for

- background variables: A study of traumatically spinal cord lesioned persons. *Spinal Cord*, 40(8), 408.
- Employment Development Institute. (2012). Panel survey of employment for the disabled. Retrieved from <https://edi.kead.or.kr/Index.do>
- Erikson, E. H. (1994). *Identity: Youth and crisis* WW Norton & Company.
- Felton, B. J., & Revenson, T. A. (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. . *Journal of Consulting and Clinical Psychology*, (52(3)), 343.
- Fernández, S., Branscombe, N. R., Gómez, Á, & Morales, J. (2012). Influence of the social context on use of surgical-lengthening and group-empowering coping strategies among people with dwarfism. *Rehabilitation Psychology*, 57(3), 224.
- Ferrin, J. M., Chan, F., Chronister, J., & Chiu, C. (2011). Psychometric validation of the multidimensional acceptance of loss scale. *Clinical Rehabilitation*, 25(2), 166-174. doi:10.1177/0269215510380836
- Finn, J. (1999). An exploration of helping processes in an online self-help group focusing on issues of disability. *Health & Social Work*, 24(3), 220-231.
- Forber-Pratt, A. J., Lyew, D. A., Mueller, C., & Samples, L. B. (2017). Disability identity development: A systematic review of the literature. *Rehabilitation Psychology*, 62(2), 198.

- Forber-Pratt, A. J., Mueller, C. O., & Andrews, E. E. (2018). Disability identity and allyship in rehabilitation psychology: Sit, stand, sign, and show up. *Rehabilitation Psychology*,
- Gardiner, E., & Iarocci, G. (2014). Students with autism spectrum disorder in the university context: Peer acceptance predicts intention to volunteer. *Journal of Autism and Developmental Disorders*, 44(5), 1008-1017.
- Gates, G. (2019). *Trauma, stigma, and autism: Developing resilience and loosening the grip of shame* Jessica Kingsley Publishers.
- Gillespie-Lynch, K., Brooks, P. J., Someki, F., Obeid, R., Shane-Simpson, C., Kapp, S. K., . . . Smith, D. S. (2015). Changing college students' conceptions of autism: An online training to increase knowledge and decrease stigma. *Journal of Autism and Developmental Disorders*, 45(8), 2553-2566.
- Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity* Simon and Schuster.
- Goodwin, D. L., & Staples, K. (2005a). The meaning of summer camp experiences to youths with disabilities. *Adapted Physical Activity Quarterly*, 22(2), 160-178.
- Goodwin, D. L., & Staples, K. (2005b). The meaning of summer camp experiences to youths with disabilities. *Adapted Physical Activity Quarterly*, 22(2), 160-178.

- Goodwin, D., Johnston, K., Gustafson, P., Elliott, M., Thurmeier, R., & Kuttai, H. (2009a). It's okay to be a quad: Wheelchair rugby players' sense of community. *Adapted Physical Activity Quarterly*, 26(2), 102-117.
- Goodwin, D., Johnston, K., Gustafson, P., Elliott, M., Thurmeier, R., & Kuttai, H. (2009b). It's okay to be a quad: Wheelchair rugby players' sense of community. *Adapted Physical Activity Quarterly*, 26(2), 102-117.
- Group, T. W. (1998). The world health organization quality of life assessment (WHOQOL): Development and general psychometric properties. *Social Science & Medicine*, 46(12), 1569-1585.
- Hahn, H. D., & Belt, T. L. (2004). Disability identity and attitudes toward cure in a sample of disabled activists. *Journal of Health and Social Behavior*, 45(4), 453-464.
- Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, 103(5), 813-821.
- Harmon, A. (2010). Nominee to disability council is lightning rod for dispute on views of autism. *New York Times*, 27
- Hermann, A. D., Lucas, G. M., & Friedrich, J. (2008). Individual differences in perceived esteem across cultures. *Self and Identity*, 7(2), 151-167.
- Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., . . . Gillberg, C. (2009). Psychiatric and psychosocial problems in adults

- with normal-intelligence autism spectrum disorders. *BMC Psychiatry*, 9(1), 35.
- Holton, A. E., Farrell, L. C., & Fudge, J. L. (2014). A threatening space?: Stigmatization and the framing of autism in the news. *Communication Studies*, 65(2), 189-207.
- Hong, Q. N., FàBregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., . . . O'Cathain, A. (2018). The mixed methods appraisal tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, (Preprint), 1-7.
- Hou, W. K., Lam, W. W. T., Law, C. C., Fu, Y. T., & Fielding, R. (2009). Measuring social relational quality in colorectal cancer: The social relational quality scale (SRQS). *Psycho-Oncology*, 18(10), 1097-1105. doi:10.1002/pon.1500
- Howard, J. A., & Renfrow, D. G. (2014). Intersectionality. *Handbook of the social psychology of inequality* (pp. 95-121) Springer.
- Hull, L., Mandy, W., Lai, M., Baron-Cohen, S., Allison, C., Smith, P., & Petrides, K. V. (2019). Development and validation of the camouflaging autistic traits questionnaire (CAT-Q). *Journal of Autism and Developmental Disorders*, 49(3), 819-833.
- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M., & Mandy, W. (2017a). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519-2534.

- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M., & Mandy, W. (2017b). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519-2534.
- Hurley, A. D., & Levitas, A. S. (2007). The importance of recognizing autism spectrum disorders in intellectual disability. *Mental Health Aspects of Developmental Disabilities*, 10(4), 157.
- Impett, E. A., Sorsoli, L., Schooler, D., Henson, J. M., & Tolman, D. L. (2008). Girls' relationship authenticity and self-esteem across adolescence. *Developmental Psychology*, 44(3), 722.
- Israelite, N., Ower, J., & Goldstein, G. (2002). Hard-of-hearing adolescents and identity construction: Influences of school experiences, peers, and teachers. *Journal of Deaf Studies and Deaf Education*, 7(2), 134-148.
- Jaarsma, P., & Welin, S. (2012). Autism as a natural human variation: Reflections on the claims of the neurodiversity movement. *Health Care Analysis*, 20(1), 20-30.
- Jiao, J., Heyne, M. M., & Lam, C. S. (2012). Acceptance of disability among chinese individuals with spinal cord injuries: The effects of social support and depression. *Psychology*, 3(9), 775-781.
doi:10.4236/psych.2012.329117
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32(1), 243-248.

Jones, J. L., Gallus, K. L., Viering, K. L., & Oseland, L. M. (2015). 'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses. *Disability & Society*, 30(10), 1490-1504.

Kaiser, S. B., Wingate, S. B., Freeman, C. M., & Chandler, J. L. (1987). Acceptance of physical disability and attitudes toward personal appearance. *Rehabilitation Psychology*, 32(1), 51.

Kang, Y. J., Park, J. K., & Gu, I. S. (2008). Validation of the self-concept and acceptance test for the people with disabilities. *Korea Employment Agency for the Disabled*, 1(1), 1-123.

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? autism and neurodiversity. *Developmental Psychology*, 49(1), 59.

Kay, T., Cavallo, M. M., Ezrachi, O., & Vavagiakis, P. (1995). The head injury family interview: A clinical and research tool. *The Journal of Head Trauma Rehabilitation*,

Keany, K. C., & Glueckauf, R. L. (1993). Disability and value change: An overview and reanalysis of acceptance of loss theory. *Rehabilitation Psychology*, 38(3), 199.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? perspectives from the UK autism community. *Autism*, 20(4), 442-462.

- Keyes, C. L. M. (1998). Social well-being. *Social psychology quarterly*, 121-140.
- Kim, J., Schilling, M. L., Kim, M., & Han, A. (2016). Contribution of leisure satisfaction, acceptance disability, and social relationship to life satisfaction among korean individuals with intellectual disability. *Journal of Mental Health Research in Intellectual Disabilities*, 9(3), 157-170.
doi:10.1080/19315864.2016.1182237
- Knight, K., Holcom, M. L., & Simpson, D. D. (1994). No title. *Psychosocial Functioning and Motivation Scales Manual*. Fort Worth: Texas Christian University, Institute of Behavioral Research.[on-Line],
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16(9), 606-613.
- Lai, M., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, 2(11), 1013-1027.
- Lai, M., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., . . . MRC AIMS Consortium. (2017). Quantifying and exploring camouflaging in men and women with autism. *Autism*, 21(6), 690-702.
- Lehnhardt, F. G., Gawronski, A., Volpert, K., Schilbach, L., Tepest, R., & Vogeley, K. (2012). Psychosocial functioning of adults with late diagnosed

- autism spectrum disorders--a retrospective study. *Fortschritte Der Neurologie-Psychiatrie*, 80(2), 88-97.
- Lewis, L. F. (2016). Exploring the experience of self-diagnosis of autism spectrum disorder in adults. *Archives of Psychiatric Nursing*, 30(5), 575-580.
- Li, L., & Moore, D. (1998). Acceptance of disability and its correlates. *The Journal of Social Psychology*, 138(1), 13-25.
doi:10.1080/00224549809600349
- Linehan, M. (2014). *DBT? skills training manual* Guilford Publications.
- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American Sociological Review*, , 400-423.
- Linkowski, D. C. (1971). A scale to measure acceptance of disability. *Rehabilitation Counseling Bulletin*,
- Livneh, H., & Antonak, R. F. (1997). *Psychosocial adaptation to chronic illness and disability*. Aspen Publishers.
- Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., Bishop, S. L., . . . Gutrie, W. (2015). *Ados-2. Manual (Part I): Modules*, , 1-4.
- Lucas, R. E. (2007). Long-term disability is associated with lasting changes in subjective well-being: Evidence from two nationally representative longitudinal studies. *Journal of Personality and Social Psychology*, 92(4), 717.

- Luhtanen, R., & Crocker, J. (1992). A collective self-esteem scale: Self-evaluation of one's social identity. *Personality and Social Psychology Bulletin*, 18(3), 302-318.
- Lynch, R. T., & Gussel, L. (1996). Disclosure and self-advocacy regarding disability-related needs: Strategies to maximize integration in postsecondary education. *Journal of Counseling & Development*, 74(4), 352-357.
- Mandy, W., Clarke, K., McKenney, M., Strydom, A., Crabtree, J., Lai, M., . . . Skuse, D. (2018). Assessing autism in adults: An evaluation of the developmental, dimensional and diagnostic Interview—Adult version (3Di-adult). *Journal of Autism and Developmental Disorders*, 48(2), 549-560.
- Mandy, W., & Lai, M. (2017a). No title. *Towards Sex-and Gender-Informed Autism Research*,
- Mandy, W., & Lai, M. (2017b). No title. *Towards Sex-and Gender-Informed Autism Research*,
- Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, 30(6), 1107-1114.
- McDonald, T. (2017). Discriminative and criterion validity of the autism spectrum identity scale (ASIS). *Journal of Autism and Developmental Disorders*, 47(10), 3018-3028.

- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine*, 151(4), 264-269.
- Nario-Redmond, M. R., Noel, J. G., & Fern, E. (2013). Redefining disability, re-imagining the self: Disability identification predicts self-esteem and strategic responses to stigma. *Self and Identity*, 12(5), 468-488.
- National Center for Health Statistics. (1998). *Data file documentation. national health interview survey on disability. phase I and phase 2, 1995 (machine readable data file and documentation. CD-ROM series 10. nos. 9 and 10)*. Hyattsville, Maryland: National Center for Health Statistics.
- NHS Improvement. (2018). *Valued care in mental health: Improving for excellence > Experts by experience*. Retrieved from https://improvement.nhs.uk/documents/3450/NHS_Mental_Health_Improvement_Chapter_1.pdf
- Nevill, R. E., & White, S. W. (2011). College students' openness toward autism spectrum disorders: Improving peer acceptance. *Journal of Autism and Developmental Disorders*, 41(12), 1619-1628.
- Nicholls, E., Lehan, T., Plaza, S. L. O., Deng, X., Romero, J. L. P., Pizarro, J. A. A., & Carlos Arango-Lasprilla, J. (2012). Factors influencing acceptance of disability in individuals with spinal cord injury in neiva, colombia, south america. *Disability and Rehabilitation*, 34(13), 1082-1088.

- Nicolaidis, C. (2012). What can physicians learn from the neurodiversity movement? *AMA Journal of Ethics*, 14(6), 503-510.
- Nilchaikovit, T. (1996). Development of thai version of hospital anxiety and depression scale in cancer patients. *J Psychiatr Assoc Thai*, 4, 18-30.
- Obeid, R., Daou, N., DeNigris, D., Shane-Simpson, C., Brooks, P. J., & Gillespie-Lynch, K. (2015). A cross-cultural comparison of knowledge and stigma associated with autism spectrum disorder among college students in lebanon and the united states. *Journal of Autism and Developmental Disorders*, 45(11), 3520-3536.
- O'brien, P., McConkey, R., & García-Iriarte, E. (2014). Co-researching with people who have intellectual disabilities: Insights from a national survey. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 65-75.
- Obst, P., & Stafurik, J. (2010). Online we are all able bodied: Online psychological sense of community and social support found through membership of disability-specific websites promotes well-being for people living with a physical disability. *Journal of Community & Applied Social Psychology*, 20(6), 525-531.
- Olkin, R. (2001). *What psychotherapists should know about disability* Guilford Press.
- Olney, M. F., Brockelman, K. F., Kennedy, J., & Newsom, M. A. (2004). Do you have a disability? A population-based test of acceptance, denial, and

- adjustments among adults with disabilities in the US. *Journal of Rehabilitation*, 70(1)
- Olney, M. F., & Kim, A. (2001). Beyond adjustment: Integration of cognitive disability into identity. *Disability & Society*, 16(4), 563-583.
- Pearson, C., & Trevisan, F. (2015). Disability activism in the new media ecology: Campaigning strategies in the digital era. *Disability & Society*, 30(6), 924-940.
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? community views and priorities from the united kingdom. *Autism*, 18(7), 756-770.
- Pellicano, L., Dinsmore, A., & Charman, T. (2013). A future made together: Shaping autism research in the UK.
- Pennebaker, J. W. (1997). *Opening up: The healing power of expressing emotions* Guilford Press.
- Pennebaker, J. W. (2004). *Writing to heal: A guided journal for recovering from trauma & emotional upheaval* New Harbinger Publications Oakland, CA.
- Ragins, B. R. (2008). Disclosure disconnects: Antecedents and consequences of disclosing invisible stigmas across life domains. *Academy of Management Review*, 33(1), 194-215.
- Ranson, N. J., & Byrne, M. K. (2014). Promoting peer acceptance of females with higher-functioning autism in a mainstream education setting: A

- replication and extension of the effects of an autism anti-stigma program. *Journal of Autism and Developmental Disorders*, 44(11), 2778-2796.
- Read, S. A. (2015). Dilemmas of stigma, support seeking, and identity performance in physical disability: A social identity approach.
- Ringdal, G., & Ringdal, K. (1993). Testing the EORTC quality of life questionnaire on cancer patients with heterogeneous diagnoses. *Quality of Life Research; an International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation - Official Journal of the International Society of Quality of Life Res*, 2(2), 129-140. doi:10.1007/BF00435732
- Rios, D., Magasi, S., Novak, C., & Harniss, M. (2016). Conducting accessible research: Including people with disabilities in public health, epidemiological, and outcomes studies. *American Journal of Public Health*, 106(12), 2137-2144.
- Robins, R. W., Hendin, H. M., & Trzesniewski, K. H. (2001). Measuring global self-esteem: Construct validation of a single-item measure and the rosenberg self-esteem scale. *Personality and Social Psychology Bulletin*, 27(2), 151-161.
- Rosenberg, M. (1979). *Conceiving the self*. 1979. Basic, New York,
- Rosenberg, M. (1965). Rosenberg self-esteem scale (RSE). *Acceptance and Commitment Therapy Measures Package*, 61, 52.

- Rubin, S. E., Chan, F., Bishop, M., & Miller, S. M. (2003). Psychometric validation of the sense of well-being inventory for program evaluation in rehabilitation. *Professional Rehabilitation*, 11(2), 54-59.
- Ryff, C. D. (1989). Happiness is everything, or is it? explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57(6), 1069.
- Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports*, 7, 40700.
- Sasson, N. J., & Morrison, K. E. (2019). First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers. *Autism*, 23(1), 50-59.
- Sasson, N. J., Morrison, K. E., Pinkham, A. E., Faso, D. J., & Chmielewski, M. (2018). Brief report: Adults with autism are less accurate at predicting how their personality traits are evaluated by unfamiliar observers. *Journal of Autism and Developmental Disorders*, 48(6), 2243-2248.
- Shakespeare, T. (1996). Disability, identity and difference. In G. Barnes & G. Mercer (Eds.), *Exploring the divide* (pp. 94–113). Leeds, England: Disability Press.

- Schwartz, S., & Meyer, I. H. (2010). Mental health disparities research: The impact of within and between group analyses on tests of social stress hypotheses. *Social Science & Medicine*, 70(8), 1111-1118.
- Shcherbakov, A. (2016). No title. *Stigma of Autism Spectrum Disorder: Cost of a Spoiled Identity*,
- Sherer, M., Maddux, J. E., Mercandante, B., Prentice-Dunn, S., Jacobs, B., & Rogers, R. W. (1982). The self-efficacy scale: Construction and validation. *Psychological Reports*, 51(2), 663-671.
- Shtayermman, O. (2009). An exploratory study of the stigma associated with a diagnosis of asperger's syndrome: The mental health impact on the adolescents and young adults diagnosed with a disability with a social nature. *Journal of Human Behavior in the Social Environment*, 19(3), 298-313.
- Simpson, D. D., Knight, K., & Ray, S. (1993). Psychosocial correlates of AIDS-risk drug use and sexual behaviors. *AIDS Education and Prevention*,
- Sinclair, J. (2013). Why I dislike "person first" language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2)
- Singh, J. (2013). Critical appraisal skills programme. *Journal of Pharmacology and Pharmacotherapeutics*, 4(1), 76.

- Smedema, S., Catalano, D., & Ebener, D. J. (2010). The relationship of coping, self-worth, and subjective well-being: A structural equation model. *Rehabilitation Counseling Bulletin*, 53(3), 131-142.
- Söderström, S. (2009). Offline social ties and online use of computers: A study of disabled youth and their use of ICT advances. *New Media & Society*, 11(5), 709-727.
- Spiegel, T., De Bel, V., & Steverink, N. (2016). Keeping up appearances: The role of identity concealment in the workplace among adults with degenerative eye conditions and its relationship with wellbeing and career outcomes. *Disability and Rehabilitation*, 38(7), 627-636.
- Sprangers, M. A. G., Te Velde, A., & Aaronson, N. K. (1999). The construction and testing of the EORTC colorectal cancer- specific quality of life questionnaire module (QLQ-CR38). *European Journal of Cancer*, 35(2), 238-247. doi:10.1016/S0959-8049(98)00357-8
- Staniland, J. J., & Byrne, M. K. (2013). The effects of a multi-component higher-functioning autism anti-stigma program on adolescent boys. *Journal of Autism and Developmental Disorders*, 43(12), 2816-2829.
- Stuifbergen, A., Becker, H., Blozis, S., & Beal, C. (2008). Conceptualization and development of the acceptance of chronic health conditions scale. *Issues in Mental Health Nursing*, 29(2), 101-114.

- Sweeney, A., Clement, S., Filson, B., & Kennedy, A. (2016). Trauma-informed mental healthcare in the UK: What is it and how can we further its development? *Mental Health Review Journal*, 21(3), 174-192.
- Tajfel, H., Turner, J. C., Austin, W. G., & Worchel, S. (1979). An integrative theory of intergroup conflict. *Organizational Identity: A Reader*, , 56-65.
- Taylor, J. A. (1953). A personality scale of manifest anxiety. *The Journal of Abnormal and Social Psychology*, 48(2), 285.
- Theran, S. A. (2010). Authenticity with authority figures and peers: Girls' friendships, self-esteem, and depressive symptomatology. *Journal of Social and Personal Relationships*, 27(4), 519-534.
- Thomas, H. (2003). Quality assessment tool for quantitative studies. *Toronto: Effective Public Health Practice Project McMaster University*,
- Tierney, S., Burns, J., & Kilbey, E. (2016). Looking behind the mask: Social coping strategies of girls on the autistic spectrum. *Research in Autism Spectrum Disorders*, 23, 73-83.
- Townend, E., Tinson, D., Kwan, J., & Sharpe, M. (2010). 'Feeling sad and useless': An investigation into personal acceptance of disability and its association with depression following stroke. *Clinical Rehabilitation*, 24(6), 555-564. doi:10.1177/0269215509358934
- Trevisan, F. (2017). Crowd-sourced advocacy: Promoting disability rights through online storytelling. *Public Relations Inquiry*, 6(2), 191-208.

- Wade, D. T. (1992). Measurement in neurological rehabilitation. *current opinion in neurology and neurosurgery*.(5(5)), 682-686.
- Willey, L. H. (2014). *Pretending to be normal: Living with asperger's syndrome (autism spectrum disorder) expanded edition* Jessica Kingsley Publishers.
- Wright, B. A. (1960). *Physical disability: A psychological approach*. New York, NY: Harper & Row. doi: 10.1037/10038-000
- Wright, B. A. (1983). *Physical disability: A psychosocial approach*. New York, NY: Harper & Row. doi: 10.1037/10589-000
- Zeldovich, L. (2018, November 7). How history forgot the woman who defined autism. *Spectrum News*. Retrieved from <https://www.spectrumnews.org/features/deep-dive/history-forgot-woman-defined-autism/>
- Zhang, T., Hu, A., Xu, H., Zheng, M., & Liang, M. (2013). Patients after colostomy: Relationship between quality of life and acceptance of disability and social support. *Chinese Medical Journal*, 126(21), 4124. doi:10.3760/cma.j.issn.0366-6999.20131160
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370.

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52(1), 30-41.

Appendices

Appendix 1: Bespoke Quality Assessment Tool

Example of completed ratings:

Study	Sample		Confounds		Measurements		Statistical analysis	
	Adequately described	Representative of target population	Authors identified all important confounds	Authors accounted for confounds (where possible)	Standardised measures	Measures meaningful to their research question	Adequately described and reported	Appropriate for study design
Example Authors (2019)	P _a	Y	P	P	Y	Y	Y	P

Note. Y = Yes (item adequately addressed); N = No (item not adequately addressed); P = Partially (item partially addressed); U = Unclear (insufficient information is provided). ^a Further explanation relating to rating if needed

Rating scale:

1. Sample (e.g. recruitment methods, participant characteristics such as age, gender, ethnicity, disability)

a. Adequately described

- i. Yes - Sufficient detail of the above areas is provided to assess the generalisability of the sample
- ii. Partially - Some detail of the above areas provided with some missing or in little detail
- iii. No - Significant detail is missing from two or more of the above areas (e.g. gender/ethnicity)

b. Representative of target population

- i. Yes - Sufficient resemblance of the target population is apparent based on the above areas
- ii. Partially - Some resemblance of the target population is apparent based on the above areas
- iii. No - No or very little resemblance of the target population is apparent
- iv. Unclear - Insufficient information is provided to rate this item

2. Confounds (non-representative sample characteristics, assistance in completing materials, time since disability onset)

a. Authors identified all important confounds

- i. Yes - All important confounds apparent in the design, materials, sample are identified by the authors
- ii. Partially - Some confounds apparent in the design, materials, sample are identified by the authors
- iii. No - No confounds are identified by the authors
- iv. Unclear - Insufficient information is provided to rate this item

b. Authors accounted for confounds (i.e. controlling, adjusting or correcting design or statistical procedures)

- i. Yes - Sufficient efforts have been made to account for apparent confounding variables
- ii. Partially - Some efforts have been made to account for apparent confounding variables
- iii. No - No efforts have been made to account for apparent confounding variables
- iv. Unclear - Insufficient information is provided to rate this item

3. Measurements (applies variables of interest, i.e. disability identity and wellbeing measures)

a. Standardised measures

- i. Yes - Validated and reliable measures are used to assess the variables of interest
- ii. Partially - One or more validated and reliable measures are used to assess the variables of interest
- iii. No - No validated and reliable measures are used to assess the variables of interest
- iv. Unclear - Insufficient information is provided to rate this item

b. Measures meaningful to their research question (concepts of interest = disability identity or wellbeing)

- i. Yes - All measures provide meaningful assessment of the concepts of interest
- ii. Partially - One or more measures provide meaningful assessment of the concepts of interest
- iii. No - None of the measures provide meaningful assessment of the concepts of interest
- iv. Unclear - Insufficient information is provided to rate this item

4. Statistics (e.g. statistical analyses performed and results found for the relevant analyses)

a. Adequately described and reported

- i. Yes - Sufficient detail is provided to assess the suitability of analyses and interpret the results
- ii. Partially - Some detail of the analyses or results provided with some missing or in little detail
- iii. No - Significant detail is missing to assess the suitability of analyses and interpret the results

b. Appropriate for study design

- i. Yes - All analyses performed are appropriate for the study design
- ii. Partially - Most analyses are appropriate for the study design (e.g. one violates an assumption)
- iii. No - None of the analyses performed are appropriate for the study design
- iv. Unclear - Insufficient information is provided to rate this item

Appendix 2: Recruitment Advert



Autistic People's Experiences of Stigma and Camouflaging

Researchers at Royal Holloway University of London are looking for autistic adults to take part in research into autistic people's experiences of camouflaging and stigma.

The study involves completing an online survey which should take approximately 25 minutes. If you complete the whole survey, you have the opportunity to enter a prize draw to win a £100 Amazon voucher.

This study has been reviewed by members of the autism community and approved by the Psychology Department ethical procedure at Royal Holloway, University of London.

For more information & to take part

please follow the link in this post
or scan the following QR code:



Link redirected possible participants to the study information and consent page (Appendix 5)

Appendix 3: Ethics Review Details



Ethics Review Details

You have chosen to submit your project to the REC for review.	
Name:	Perry, Ella (2016)
Email:	NDJT008@live.rhul.ac.uk
Title of research project or grant:	Autistic People's Experiences Stigma and Camouflaging
Project type:	Royal Holloway postgraduate research project/grant
Department:	Psychology
Academic supervisor:	Dr Eilidh Cage
Email address of Academic Supervisor:	eilidh.cage@rhul.ac.uk
Funding Body Category:	No external funder
Funding Body:	
Start date:	01/09/2018
End date:	01/07/2019

Research question summary:

Autistic people show differences in their social communication, sensitivity to sensory stimulation and the nature of their interests (APA, 2013). Some autistic people describe using strategies to 'hide' autistic traits to look 'non-autistic' in social situations, which has been termed 'camouflaging' (Bargiela, Steward & Mandy, 2016). Autistic people who report using camouflaging strategies describe difficulties with anxiety and show higher symptoms of depression (Bargiela et al., 2016; Cage, Di Monaco & Newell, 2017; Hull et al., 2017). Given the high lifetime prevalence of mental health difficulties in autistic people (Lerndart et al., 2011), understanding factors that may put autistic adults at higher risk of mental health difficulties is imperative.

One untested theory, is that camouflaging represents a response to stigma. Tajfel & Turner's (1979) social identity theory proposes that individuals in stigmatized groups may use "individualistic" and "collective" strategies to reduce the discrimination they experience. Camouflaging may be likened to individualistic strategies that involve dissociating and distancing oneself from one's group to improve one's individual status. Collective strategies include methods to re-define one's group to improve the status of the whole group. This could involve participating in autism rights or community groups and re-evaluating negative assumptions about autism. Individualistic strategies are thought to impact on psychological wellbeing through processes involving one's sense of belonging, self-esteem and feelings of guilt (Branscombe et al, 2012). Collective strategies may have a protective effect on wellbeing through enhanced group membership and social support (Tajfel & Turner, 1979).

If camouflaging does represent an individualistic strategy, one may hypothesise that it positively relates to autism related stigma, individualistic strategy use and psychological wellbeing. Further, collective strategy use may provide a protective effect on wellbeing. Accordingly, this study aims to explore; How autism related stigma, individualistic and collective strategy use relate to camouflaging incidence and psychological wellbeing?

Research method summary:

Adults with a diagnosis of ASC will be recruited via online and offline communities through snowballing methods (e.g. Twitter, autism community forums, charities and word-of-mouth). Participants will be invited to complete six measures as part of an online or paper questionnaire and offered entry into a £100 voucher prize draw for participation.

Measures include:

- 1) The Camouflaging Autistic Traits Questionnaire (CAT-Q; Hull et al, in development), a 25-item self-report measure of camouflaging.
- 2) Individual-level strategy use (Nario-Redmond et al., 2013), a 13-item measure of individualistic-strategy use (original scale relates to disability identity has been adapted to autistic identity).
- 3) Group-level strategy use (Nario-Redmond et al., 2013), a 13-item measure of collective-strategy use (adapted to autistic identity).
- 4) The Stigma Consciousness Scale (SCS; Link and Whelan, 2014), a 5 item scale that assesses awareness of stigmatized status and treatment (adapted to autism).
- 5) Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS), is a 14 item measure of wellbeing. The items are all worded positively and cover both feeling and functioning aspects of mental wellbeing.
- 6) The Ritvo Autism and Asperger Diagnostic Scale (RAADS-14; Eriksson, Andersen & Bejerot., 2013) is a 14-item self-report screening tool for ASC in adult psychiatric populations based on DSM-IV-TR and ICD-10 diagnostic criteria for autism and Asperger's syndrome.

The study is a cross-sectional, single group, correlational study, with individual-level strategy use (individual strategy use scale), autism related stigma (SCS) and wellbeing (WEMWBS) as the predictor variables, and camouflaging (CAT-Q) as the dependent variable. RAADS- 14 scores are used to confirm presence of autistic traits and do not feature in the analyses. A required sample size of 77 participants has been calculated on the basis of a multiple linear regression using 4 predictors, with predicted power of 0.8 and small effect size (0.15).

Risks to participants

Does your research involve any of the below? Children (under the age of 16), No

Participants with cognitive or physical impairment that may render them unable to give informed consent, No

Participants who may be vulnerable for personal, emotional, psychological or other reasons, Yes

Participants who may become vulnerable as a result of the conduct of the study (e.g. because it raises sensitive issues) or as a result of what is revealed in the study (e.g. criminal behaviour, or behaviour which is culturally or socially questionable), Yes

Participants in unequal power relations (e.g. groups that you teach or work with, in which participants may feel coerced or unable to withdraw), No

Participants who are likely to suffer negative consequences if identified (e.g. professional censure, exposure to stigma or abuse, damage to professional or social standing), No

Details,

Whilst the sample is non-clinical, as participants will be recruited via snowballing and word of mouth methods, some participants may possess particular vulnerabilities. Accessible information (i.e. clear and straightforward language) about the content of the study will be

presented in the study advertisements to ensure participants are informed prior to participation. Furthermore, accessible information signposting participants towards help for mental health difficulties and a full debrief will be provided at the end of the survey (or emailed to participants who do not complete the survey), to enable participants to seek relevant support should the questionnaire raise sensitive issues.

It is possible that completion of measures relating to one's experience of stigma and wellbeing will raise sensitive issues for some participants and that participants may have pre-existing vulnerabilities. Measures included have been carefully screened and adjusted to reduce potential distress that could arise. For example, the WEMWBS to measure wellbeing was selected due to its inclusion of positively framed statements i.e. "I've been feeling good about myself". Further, negatively framed statements in other measures such as "I support aims to 'cure' autism." in the Individual-level strategies questionnaire have been reframed to reduce potential distress this could evoke (e.g. "I do not support aims to 'cure' autism" which is now reverse scored).

Design and Data

Does your study include any of the following?

Will it be necessary for participants to take part in the study without their knowledge and/or informed consent at the time?, No

Is there a risk that participants may be or become identifiable?, No

Is pain or discomfort likely to result from the study?, No

Could the study induce psychological stress or anxiety, or cause harm or negative consequences beyond the risks encountered in normal life?,
No

Does this research require approval from the NHS?, No

If so what is the NHS Approval number,

Are drugs, placebos or other substances to be administered to the study participants, or will the study involve invasive, intrusive or potentially harmful procedures of any kind?, No

Will human tissue including blood, saliva, urine, faeces, sperm or eggs be collected or used in the project?, No

Will the research involve the use of administrative or secure data that requires permission from the appropriate authorities before use?, No

Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?, No

Is there a risk that any of the material, data, or outcomes to be used in this study has been derived from ethically-unsound procedures?, No

Details,

Risks to the Environment / Society

Will the conduct of the research pose risks to the environment, site, society, or artifacts?, No

Will the research be undertaken on private or government property without permission?, No

Will geological or sedimentological samples be removed without permission?, No

Will cultural or archaeological artifacts be removed without permission?, No

Details,

Risks to Researchers/Institution

Does your research present any of the following risks to researchers or to the institution?

Is there a possibility that the researcher could be placed in a vulnerable situation either emotionally or physically (e.g. by being alone with vulnerable, or potentially aggressive participants, by entering an unsafe environment, or by working in countries in which there is unrest)?, No

Is the topic of the research sensitive or controversial such that the researcher could be ethically or legally compromised (e.g. as a result of disclosures made during the research)?,No

Will the research involve the investigation or observation of illegal practices, or the participation in illegal practices?, No

Could any aspects of the research mean that the University has failed in its duty to care for researchers, participants, or the environment / society?,No

Is there any reputational risk concerning the source of your funding?, No

Is there any other ethical issue that may arise during the conduct of this study that could bring the institution into disrepute?, No

Details,

Declaration

By submitting this form, I declare that the questions above have been answered truthfully and to the best of my knowledge and belief, and that I take full responsibility for these responses. I undertake to observe ethical principles throughout the research project and to report any changes that affect the ethics of the project to the University Research Ethics Committee for review.

Certificate produced for user ID, NDJT008

Date:	02/08/2018 10:08
Signed by:	Perry, Ella (2016)
Digital Signature:	Ella Perry
Certificate dated:	8/2/2018 10:57:00 AM
Files uploaded:	Ella Perry - Info and Consent form.docx Ella Perry - thesis measures.docx Ella Perry - Debrief form .docx

Appendix 4: Ethical Approval

Result of your application to the Research Ethics Committee (application ID 1040)

Ethics Application System <ethics@rhul.ac.uk>

Sat 20/10/2018 20:53

To: Perry, Ella (2016) <Ella.Perry.2016@live.rhul.ac.uk>; Cage, Eilidh <Eilidh.Cage@rhul.ac.uk>; ethics@rhul.ac.uk
<ethics@rhul.ac.uk>;

PI: Dr Eilidh Cage

Project title: Autistic People's Experiences Stigma and Camouflaging

REC ProjectID: 1040

Your application has been approved by the Research Ethics Committee.

Please report any subsequent changes that affect the ethics of the project to the University Research Ethics Committee
ethics@rhul.ac.uk

Appendix 5: Study Information and Consent Form



Department of Psychology

Consent Form

Autistic People's Experiences Stigma and Camouflaging

This research is being conducted by Ella Perry, a Doctoral student in Clinical Psychology, under the supervision of Dr. Eilidh Cage (Department of Psychology, Royal Holloway, University of London) and Dr. Will Mandy (The Department of Clinical, Educational & Health Psychology, University College London). It has been reviewed by members of the autism community.

This research focuses on developing our understanding of autistic people's experiences of camouflaging and stigma. We define camouflaging as strategies people use (with or without conscious awareness) to try to hide or mask traits of autism in order to look 'non-autistic' or 'neurotypical'. We understand stigma as experiences of exclusion or discrimination as an autistic person. Our research aims to understand how camouflaging may relate to experiences of stigma and psychological well-being.

We hope that your answers will help us understand how autistic people's experiences of stigma impact on their social and psychological lives, in particular to what extent they engage in camouflaging and their psychological well-being. Even if you do not feel you experience autism-related stigma or camouflage, your answers will still be very helpful to add to our understanding.

If you agree to participate, you will be asked to complete an online survey which should take approximately 25 minutes. The survey will include questions related to your experiences and responses to autism-related stigma, camouflaging, and psychological well-being. At the end of the survey you will be asked some questions about yourself, so that we have an understanding of the types of people who have completed the survey.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason and you

may choose not to answer any question in the questionnaire, without giving a reason.

The only people who will have access to your answers are the researchers. In the study, you will be known only by an ID number, and the data will be stored securely and password protected. Your data will be treated with full confidentiality and, if this research is published, the data you provide will not be identifiable as yours. If you would like to discuss any aspect of the research or your participation don't hesitate to contact Ella Perry (ella.perry.2016@live.rhul.ac.uk).

This study has been reviewed and approved by the Psychology Department ethical procedure at Royal Holloway, University of London.

If you complete the whole survey, you have the opportunity to enter a prize draw to win a £100 Amazon voucher by providing your email address so we can contact you if you win. These details will be stored separately from your answers to the online survey questions, thus protecting your anonymity.

You have been asked to participate in a study about autism camouflaging and stigma.

Have you:

	Yes	No
Read the information about the study?	<input type="checkbox"/>	<input type="checkbox"/>
Understood that you're free to withdraw from the study at any time, without giving a reason?	<input type="checkbox"/>	<input type="checkbox"/>
Understood that you're free to omit answering any question from the study at any time, without giving a reason?	<input type="checkbox"/>	<input type="checkbox"/>
Agreed to take part in the study?	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 6: Study Debrief Form



Department of Psychology Debrief

Thank you very much for participating in this research, your answers will be very helpful to us in trying to better understand camouflaging in autism.

If you would like to enter the prize draw to win a £100 amazon voucher, please [\[click on this link\]](#) – this will take you to a separate page, so that your details are stored securely and separately from your answers in the survey.

What was the study about?

Through the use of this survey, we aim to collect information that can be used to address two main research themes within the context of camouflaging in autism: 1) experiences and responses to autism-related stigma; 2) psychological wellbeing.

The Two Themes:

Experiences and Responses to Autism-Related Stigma

Research shows that autistic people experience autism-related stigma (Beardon & Edmons, 2007; Cameron, 2014). Some evidence suggests that when people experience stigma they use different strategies to reduce the discrimination they face (Branscombe, Fernandez, Gomez, & Cronin, 2012). We want to know whether camouflaging behaviour is used as a strategy by autistic people to cope with stigma.

Psychological Wellbeing

Whilst researchers have linked camouflaging to experiencing mental health difficulties, more research is needed to understand the impact camouflaging behaviours might have on psychological wellbeing. In the current research, we are interested in whether psychological wellbeing relates to camouflaging behaviour, stigma and the strategies people use to cope with stigma.

What happens next?

Once all of the data is collected it will be analysed, written up and submitted as part of my Doctoral thesis and for publication in academic journals. The

results from this study will examine some of the complexities surrounding camouflaging in autism and potentially aid our understanding of well-being in autistic people.

Further information:

If you would like any further information or have any other questions, you can contact Ella Perry at ella.perry.2016@live.rhul.ac.uk

If you have found any questions in this survey upsetting or would like some further information, you could contact the following organisations (please note that the links will open in a new window):

- The Samaritans (website: www.samaritans.org, call for free 116 123 (UK))
- Mind (website: www.mind.org.uk/)
- The National Autistic Society (website: www.autism.org.uk, helpline 0808 800 4104 (UK))
- You can also find autism groups in your area (in the UK) through the NHS website: <http://www.nhs.uk/Service-Search/Autism%20support%20groups/LocationSearch/310>

Thank you for your participation!

Appendix 7: Individualistic Strategy Use Scale

Individualistic strategies

(Adapted from Nario-Redmond et al., 2013)

In this section, there are 13 statements about hiding autistic behaviours and identifying with [being autistic/having autism].

We recommend that you do not spend too much time rating each statement, but select the option that you feel intuitively best describes your experiences.

	Strongly disagree	Disagree	Disagree somewhat	Neutral	Agree somewhat	Agree	Strongly agree
1. I try to hide my autistic behaviours from others in certain situations.							
2. I frequently 'pass' as a [person without autism/non-autistic person] or 'neurotypical' person.							
3. I try to hide my autistic behaviours whenever I can							
4. I am able to hide my autism							
5. Overall, [being autistic/having autism] has very little to do with how I feel about myself.							
6. I don't think of myself as a [person with autism/autistic person]							
7. I am not disabled.							
8. Being a [person with autism/autistic person] is important to who I am*							
9. I often think of myself as a [person without autism/non-autistic person] or neurotypical person							

10. I would prefer not to [be autistic/have autism]							
11. I do not need to be “cured” of autism.*							
12. I do not support aims to “cure” autism.*							
13. I do not identify with people who are trying to “overcome” autism*							

Scoring:

All items are scored 1-7. Items with an asterisk () should be reverse scored.*

Factors:

CONCEALING STATUS = 1-4

DENY/MINIMIZE = 5-9

ATTEMPT TO OVERCOME = 10-13

Appendix 8: Collective Strategy Use Scale

Collective strategies scale

(Adapted from Nario-Redmond et al., 2013)

In this section, there are 13 statements about what it means to [be autistic/have autism] and participate in the autism community.

We recommend that you do not spend too much time rating each statement, but select the option that you feel intuitively best describes your experiences.

	Strongly disagree	Disagree	Disagree somewhat	Neutral	Agree somewhat	Agree	Strongly agree
1. [Being autistic/having autism] is a strength.							
2. [Being autistic/having autism] enriches my life.							
3. I am proud to [be autistic/have autism].							
4. I would not change [being autistic/having autism] even if I could.							
5. I like it when [people with autism/autistic people] use the words “autistic” or “Aspie” in a positive manner.							
6. I believe in “autism pride.”							
7. It is important to build an autism community.							
8. I have a lot of pride in the autism community.							
9. Autistic culture is alive and well.							
10. I am a better person because of my autism.							
11. I am an autism rights activist.							
12. I advocate for the rights of [autistic people/people with autism].							

13. I do not want to participate in protests for autism rights.*							
--	--	--	--	--	--	--	--

Scoring:

All items are scored 1-7. Items with an asterisk () should be reverse scored.*

Factors:

VALUING EXPERIENCE = 1-5

COMMUNITY PRIDE = 6-10

CIVIL RIGHTS APPROACH/ SOCIAL CHANGE ACTIVISM = 11-13

Appendix 9: The Stigma Consciousness Scale

The Stigma Consciousness Scale

(Adapted from Link & Whelan, 2014)

In this section, there are 5 statements about experiences of stigma or discrimination as a [person with autism/autistic person].

Please select the option that best describes your experiences.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. Stereotypes about [people with autism/autistic people] have not affected me personally				
2. Most people do not judge someone on the basis of them [being autistic/having autism]				
3. People knowing that I [am autistic/have autism] does not influence how they act towards me				
4. I almost never think about the fact that I [be autistic/have autism] when I'm around others				
5. I think that people are often unfairly accused of being biased against [people with autism/autistic people]				

Scoring:

All items are scored 0-3. Items with an asterisk () should be reverse scored.*

Appendix 10: The Camouflaging Autistic Traits Questionnaire

Camouflaging Autistic Traits Questionnaire

(Hull et al., 2018)

In this section, there are 25 statements about your behaviour, intentions and experiences during social interactions.

We recommend that you do not spend too much time rating each statement, but select the option you feel intuitively best describes your experiences.

	Strongly disagree	Disagree	Disagree somewhat	Neutral	Agree somewhat	Agree	Strongly agree
1. When I am interacting with someone, I deliberately copy their body language or facial expressions							
2. I monitor my body language or facial expressions so that I appear relaxed							
3. I rarely feel the need to put on an act in order to get through a social situation*							
4. I have developed a script to follow in social situations (for example, a list of questions or topics of conversation)							
5. I will repeat phrases that I have heard others say in the exact same way that I first heard them							
6. I adjust my body language or facial expressions so that I appear interested by the person I am interacting with							
7. In social situations, I feel like I'm 'performing' rather than being myself							

8. In my own social interactions, I use behaviours that I have learned from watching other people interacting							
9. I always think about the impression I make on other people							
10. I need the support of other people in order to socialise							
11. I practice my facial expressions and body language to make sure they look natural							
12. I don't feel the need to make eye contact with other people if I don't want to*							
13. I have to force myself to interact with people when I am in social situations							
14. I have tried to improve my understanding of social skills by watching other people							
15. I monitor my body language or facial expressions so that I appear interested by the person I am interacting with							
16. When in social situations, I try to find ways to avoid interacting with others							
17. I have researched the rules of social interactions (for example, by studying psychology or reading books on human behaviour) to improve my own social skills							
18. I am always aware of the impression I make on other people							
19. I feel free to be myself when I am with other people*							

20. I learn how people use their bodies and faces to interact by watching television or films, or by reading fiction							
21. I adjust my body language or facial expressions so that I appear relaxed							
22. When talking to other people, I feel like the conversation flows naturally*							
23. I have spent time learning social skills from television shows and films, and try to use these in my interactions							
24. In social interactions, I do not pay attention to what my face or body are doing*							
25. In social situations, I feel like I am pretending to be 'normal'							

Scoring:

All items are scored 1-7, with higher scores reflecting greater camouflaging. Items with an asterisk () should be reverse scored.*

Factors:

Compensation = 1, 4, 5, 8, 11, 14, 17, 20, 23

Masking = 2, 6, 9, 12, 15, 18, 21, 24

Social Awkwardness = 3, 7, 10, 13, 16, 19, 22, 25

Appendix 11: Warwick-Edinburgh Mental Wellbeing Scale

Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

In this section, there are 14 statements about feelings and thoughts.

Please select the option that best describes your experience over the last 2 weeks

Statements	None of the time	Rarely	Some of the time	Often	All of the time
1. I've been feeling optimistic about the future					
2. I've been feeling useful					
3. I've been feeling relaxed					
4. I've been feeling interested in other people					
5. I've had energy to spare					
6. I've been dealing with problems well					
7. I've been thinking clearly					
8. I've been feeling good about myself					
9. I've been feeling close to other people					
10. I've been feeling confident					
11. I've been able to make up my own mind about things					
12. I've been feeling loved					
13. I've been interested in new things					
14. I've been feeling cheerful					

Scoring:

All items are scored 1-5.

Appendix 12: Ritvo Autism and Asperger Diagnostic Scale

The RAADS-14 Screen

In this section, there are 14 statements about your experiences of social interactions, sensory stimulation and routine.

For each statement, please select from the following options according to what is most true for you:

- This is true or describes me now and when I was young.
- This was true or describes me only now (refers to skills acquired).
- This was true only when I was young (16 years or younger).
- This was never true and never described me.

	True now and when I was young	True only now	True only when I was younger than 16	Never true
1. It is difficult for me to understand how other people are feeling when we are talking				
2. Some ordinary textures that do not bother others feel very offensive when they touch my skin				
3. It is very difficult for me to work and function in groups				
4. It is difficult to figure out what other people expect of me				
5. I often don't know how to act in social situations				
6. I can chat and make small talk with people*				
7. When I feel overwhelmed by my senses, I have to isolate myself to shut them down				

8. How to make friends and socialise is a mystery to me				
9. When talking to someone, I have a hard time telling when it is my turn to talk or to listen				
10. Sometimes I have to cover my ears to block out painful noises (like vacuum cleaners or people talking too much or too loudly)				
11. It can be very hard to read someone's face, hand, and body movements when we are talking				
12. I focus on details rather than the overall idea				
13. I take things too literally, so I often miss what people are trying to say				
14. I get extremely upset when the way I like to do things is suddenly changed				

Items with an asterisk () should be reverse scored.*